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ABSTRACT

This document includes summaries of papers and discussions presented at the first of three federally supported, national conferences on the development of policy and practices to implement the Individuals with Disabilities Education Act related to invasive procedures for children with special health care needs. Emphasis is on the interdisciplinary discussion of issues by special educators, lawyers, physicians, nurses, ethicists, paraprofessionals, health finance professionals, and parent advocates. Individual sessions with multiple presenters addressed the following topics: medical and legal issues; quality of care (structures that allow for safe and legal delegation); issues in special education (inclusion); issues of ethics, advocacy, and funding; systems change (how to influence policy making); challenges for the future and funding; and the creation of action plans. Extensive appendices include a list of speakers, addresses of advisory group and board members, speaker handouts, an annotated bibliography, reprinted articles, and ordering information for the Model Nurse Practice Act. (DB)

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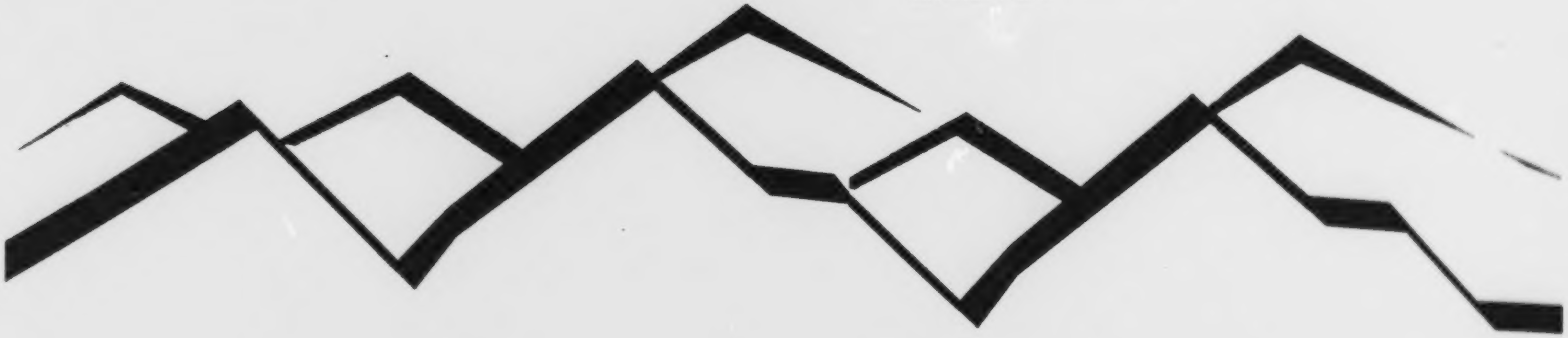

PROCEEDINGS OF THE NATIONAL CONFERENCE ON DEVELOPING POLICY AND PRACTICE TO IMPLEMENT I.D.E.A. RELATED TO INVASIVE PROCEDURES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

University of Colorado Health Sciences Center
School of Nursing

EC 303 996

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A SUMMARY OF THE
PROCEEDINGS OF THE
NATIONAL CONFERENCE ON
DEVELOPING POLICY AND PRACTICE TO IMPLEMENT I.D.E.A.
RELATED TO INVASIVE PROCEDURES FOR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Edited: Marilyn J. Krajicek, EdD, RN, FAAN
Geraldine D. Steinke, PhD

August 6 - 7, 1994

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We also express our appreciation of the professional contributions of our speakers (not already named above) including: Ms. Julie Beckett, Ms. Kathleen Brendza, Mr. Jim Carlisle, Ms. Rethea Fordyce, Ms. Mary Anne Harvey, Ms. Mary Hicks, Ms. Kit Hovey, Ms. Ashley Hovey, Dr. Clair Martin, Dr. Brian McNulty, Dr. John Nackashi, The Honorable Patricia Schroeder, Dr. Fred Smokoski, Dr. Kayo Sunada, and Dr. Mark Yarborough; as well as of project consultants including Drs. Sandy Larson, Carolie Coates and Don Soltz.

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Marilyn J. Krajicek, EdD, RN, FAAN
and
Geraldine Steinke, Ph.D.
Editors

PREFACE

Since the mid 1970s, inclusion has been issue of national concern and attention. During the same period advances in medicine have enabled the survival and increased mobility of children who are medically fragile or dependent upon technology. As these young children are presented for admission to public school and child care programs, special educators, general educators, child care providers, and parents are increasingly challenged to meet an unprecedented array of health care needs. Yet, as costs escalate and funds for education and child care become scarcer, the on-site nurse becomes an increasing rarity. Thus, while accomplishing their primary missions of education and child care, administrators, educators (special and general), child care providers and paraprofessionals must address a growing number of complex health care needs among their charges.

Are Schools of Special Education, and programs educating those who serve these children and their families, preparing their graduates to address special health care needs in a safe and legal manner? Do curricula in education and early child care address complex health issues, federal laws related to children with special needs, and state laws (such as Nurse Practice Acts) that may either hinder or facilitate compliance with federal laws?

It is incumbent upon Schools of Special Education and program engaged in pre-service education, training, or continuing education of those serving to children and families to ensure that their students are alerted to the complex issues concerning children with special health care needs. Students must be made aware of: (a) the rights of the children under federal laws to receive free and appropriate public education in the least restrictive environment possible (e.g., IDEA, ADA), (b) the nature of invasive health care procedures required by some young children, (c) the conditions for safe provision of these procedures, (d) the legal status in their state of delegation and supervision of nursing tasks to non-health licensed individuals (Nurse Practice Acts), and (e) related issues of agency and personal liability. Issues of ethics, advocacy, systems change, funding, and future challenges are also germane, especially to those working in, or aspiring to, administrative roles in services for children.

As the first in a series of three federally supported, national conferences, the following *Proceedings* of the 1994 Conference documents the interdisciplinary discussion of these issues by special educators, lawyers, physicians, nurses, ethicists, paraprofessionals, health finance professionals, and parent advocates of children with special needs. It also presents models and resources for the safe and legal implementation of IDEA related to invasive health care procedures for young children.

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As part of a three-year special project to provide information to state and local communities about the development of the appropriate policy, practice, and training opportunities needed to implement the Individuals with Disabilities Education Act (IDEA) as related to invasive health care procedures the first National Conference on Developing Policy and Practice to Implement IDEA Related to Invasive Procedures for Children with Special Health Care Needs was held in Denver, Colorado, on August 6 - 7, 1994. The conference attracted speakers and attendees from 17 states, who represented multiple disciplines and diverse levels of responsibility for policy definition and implementation.

The purposes of the Conference were to address issues of awareness, liability, and the need for training and dissemination in the implementation of IDEA related to invasive health care procedures. More specifically its objectives were to

- increase awareness of state leadership personnel of the need to examine legal obligations and constraints, their understanding of what the special health care needs are for infants and young children with complex medical needs, and their recognition of interagency cooperation needs to serve this special population in mainstream settings;
- examine and set forth appropriate laws, regulations, and standards for safe delegation of nursing tasks to non-health professionals and paraprofessionals; and
- provide training models and disseminate proceedings and resource guide to provide notification of availability of training to prepare personnel for safe, legal administration of medically invasive procedures.

Background

Medical and health-related technological advances preserve the lives of many children who would not have survived 20 years ago (Kohrman, 1992). However, many of the surviving children have medically complex needs and require invasive health care procedures as part of their daily lives.

Federal legislation mandates that all children, including children with special health care needs (CSHCN), receive free and appropriate public education (FAPE) in the least restrictive environment (LRE) possible. So that health status does not serve as an obstacle to integration of CSHCN with their peers, the related services required by CSHCN must be provided.

Charged with implementing the Public Laws and amendments such as Individuals with Disabilities Education Act (IDEA), day care programs and public schools are increasingly challenged to educate children with complex medical and health-related needs who require invasive health care procedures such as clean intermittent catheterization and G tube feeding. While invasive health care procedures are typically regarded as nursing tasks, day care and education settings may lack resources and appropriately trained and credentialed personnel to perform the required procedures. Moreover, laws at the state level, such as Nurse Practice Acts, may complicate or explicitly prohibit the delegation and supervision of the required tasks to non health-licensed personnel.

Since the children will be increasingly present, the delivery of safe and legal care is an issue of paramount national importance that will be resolved in the evolution of policy and practice on the state and local levels. Those responsible for defining and implementing policy must: (a) understand the diverse needs of technologically dependent and medically fragile children; (b) address applicable state and federal laws; (c) recognize the uniqueness of service networks across states and within localities; (d) adapt to differential funding mechanisms for the provision of services; (e) acknowledge and incorporate interdisciplinary concerns; and (f) address normative and cultural expectations of families receiving the services.

Conference Design

Burrian (1989) describes policy as a dynamic, evolving phenomenon enmeshed in networks of related activities -- a "macrodecision" (p. 95) resulting from a formal or informal multi-decision process. This paradigm is particularly applicable to the implementation of IDEA related to invasive procedures where policy development in multiple domains overlap in an ongoing process. Those charged with defining and implementing policy in one domain may discover their decisions conflict with those from other domains, including law, ethics, technology, health, education, and child advocacy. Thus, the first Policy and Practice Conference was designed from an interdisciplinary perspective representing relevant policy areas to identify the parameters and provide examples for policy development, practice guidelines, and training of personnel in the performance of invasive procedures for CSHCN.

To this end, the Conference sessions addressed

- medical/legal issues;
- the structure that allows for safe and legal delegation;
- issues in special education - inclusion;
- issues of ethics, advocacy, funding;
- systems change; and
- challenges for the future.

Finally, utilizing breakout sessions paralleling the focal topics of the panel and discussion groups, participants had the opportunity to design individualized Action Plans. The plans described participant-defined objectives and strategies for achieving innovative approaches to state and national issues affecting the implementation of IDEA related to invasive procedures.

Notes to the Reader

As noted previously, invasive health care procedures are generally regarded as nursing tasks. Their performance in day care and school settings broadens the issue to interdisciplinary status involving (among others) administrators, educators, early childhood interventionists, physicians, nurses, paraprofessionals, and child advocates, as well as parents. While many of these diverse perspectives were represented in the Conference panel and discussion sessions, the overall focus was safe and legal performance of invasive health care procedures.

Parents are the best teachers in conveying their own children's needs and preferences. However, to minimize risks to the safety of the children, as well as to minimize agency and personal liability, the delegation of performance of invasive procedures to educators and paraprofessionals must be done in collaboration with parents and a properly licensed health professional, in accordance with prevailing practice laws and regulations. Once safely and legally delegated, the issue of monitoring ongoing adherence to established procedures for performance of invasive health care procedures becomes critical. As the number of children requiring diverse invasive procedures increases in educational and day care programs, the risks of problems and liability will also escalate. It is therefore essential that policy makers and providers of education, services and care are knowledgeable about the issues and accountable for their decisions and behavior.

Maximal integration of children with special health care needs with their peers requires creation and execution of policies and procedures to permit safe and legal delegation. This requires up-to-date knowledge of the appropriate laws and associated regulations, and where applicable, amendment of Nurse Practice Acts that prohibit delegation. Also required is identification of appropriate people and resources to disseminate policy and practice knowledge on the state level and, on the local level, to teach content regarding the performance of specific procedures. Readers are encouraged to utilize the resources of their state boards of nursing, schools of nursing, and state and local health departments, as well as resources noted in these *Proceedings*, to acquire and maintain state- and locality-specific information on these issues.

Structure of the *Proceedings*

The body of these *Proceedings* is organized by session, including presenter-authored papers or abstracts, conference presentation summaries (merging several staff recorders notes), or augmented abstracts (presenter-authored outlines integrated with conference presentation summaries). Reports of presentations are followed by a synopsis of the Open Discussion that followed each group of presentations.

The Appendices to the *Proceedings* include speaker handouts, or where those handouts could not be feasibly reproduced, annotated bibliographies and information on accessing the materials directly from the from the speaker. Also included is the Policy and Practice Resource Table and Ordering Information, prepared by conference staff.

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August 6, 1994

WELCOMING REMARKS

SPEAKER: **Clair Martin, PhD, RN, FAAN**
Dean and Professor, University of Colorado School of Nursing

As part of a three-year special project to provide information to state and local The rapid social change, including technological advances and economic changes, that now characterize our society make it difficult for human services providers to follow earlier practices in anticipating society's needs. The rapid rate of such changes often demands action before policies and guidelines are available to guide decision-making.

Inclusion of children whose special health care needs require invasive procedures is clearly one such area where the demand for action outpaces the establishment of policies, regulations and guidelines. Therefore, this Policy & Practice Conference is an important effort to support parents, educators, and health care providers struggling to resolve conflicting systems and requirements for the benefit of the children. *(Staff summary)*

SPEAKER: **Marilyn Krajicek, EdD, RN, FAAN**
Project Director, Policy and Practice to Implement IDEA
Associate Professor, University of Colorado School of Nursing

The purpose of this conference is to focus on children with special health care and educational needs. The conference evolved from efforts begun in 1985, with Dr. Ann Smith, to explore the paraprofessional model, more specifically training paraprofessionals in child care centers and early child education settings. Original funding was from a Personnel Preparation grant from the US Department of Education to pursue content related to invasive procedures in program entitled First Start.

Initial efforts to address invasive procedures were challenged by the Colorado Attorney General on the grounds that teaching invasive procedures to paraprofessionals violated the Colorado Nurse Practice Act. Teaching as a team in other states, Drs. Smith and Krajicek contacted other State Boards of Nursing and found that violation of their Nurse Practice Acts was also likely. So, content related to invasive procedures was removed from the First Start curriculum during the period 1986-1992.

A statewide Colorado task force, chaired by Marie Swigert and including several conference participants, determined that, as we approach full implementation of IDEA, the implications of this issue extend beyond nursing. IDEA, as it relates to invasive procedures and the welfare of the children, is equally the concern of educators, paraprofessionals, administrators, health care providers, parents and other concerned parties.

Within the framework of implementing inclusion amidst the environment of health care reform, the Conference will

- identify issues that must be examined for inclusion;
- address providers' legal responsibilities; and
- address State laws regarding early childhood interventions.

The conference will not answer all of the questions. It will probably raise more questions than it answers. Thus, the Conference will raise *process* issues for providing high quality care to children with special health care and educational needs and their families. It is our hope that your participation will enable each of you to take back to your state both information and an agenda to facilitate an interdisciplinary dialogue among health and education providers and parents. *(Staff summary)*

WHY WE ARE HERE: Medical and Legal Issues

MODERATOR: Marjorie Long, JD
Attorney at Law, Legal Consultant

SPEAKER: Brian McNulty, PhD
Assistant to the Commissioner
Colorado Department of Education

Colorado: A State Perspective

While PL 94-142 was passed in 1975, it was not until 1986 that PL 99-457 was passed by the U.S. Congress. This was in part due to the fact that so few early childhood programs and services were available and that there was not a constituency large enough to effect this change.

Now that we have PL 94 457 and have mandated services for 3-5 year old children with disabilities (Section 619) and are moving towards full services for infants and toddlers (Part H), what should we do differently? What have we learned over the past 20 years? What services should we provide and how and where should they be provided?

I would like to propose that we radically redesign our service system in a way that better meets the needs of children with disabilities and their families. While not being able to go into great detail here, I would propose two major considerations:

1. The service delivery model must become more family focused and family directed.
2. The services must be provided in the most natural settings possible.

Overall, I would suggest that we are experiencing a shift in the model of how we service children with disabilities and their families. Specifically this involves four major components:

1. Movement away from the "medical" or "disability" model to an "ability" model. Rather than focusing on deficits, we, instead, should be building on strengths and abilities that the child and the family have. This shift also means integrating our services into more naturalistic settings and not providing separate "special education only" programs.

2. Movement away from teacher directed interventions to child initiated and directed services. The whole move should be towards developmentally appropriate practices" that are age appropriate. While these practices are prevalent in typical early childhood settings, they need to be the norm for all children.

3. Movement away from discipline specific interventions to more holistic multidisciplinary interventions and supports. Kids don't come in parts and shouldn't be viewed or served as if they did. This issue becomes most evident when we look at providing services in more natural settings.

4. Movement away from a focus on the child to a focus on the family. Families are ecological systems. If we intervene in any part, we affect the entire system. We must increase our awareness and understanding of how to support families in ways that they see as helpful.

In Colorado we have tried to address these issues through a "value-based" decision making model. The state interagency council developed a set of values or guiding principals to assure that we supported only initiatives that moved us towards our vision. These values included:

- Children and families are valued for their unique capacities, experiences, and potential.

- Families have the right and responsibility to make decisions on behalf of their children and themselves.

- Communities are enhanced by recognizing and honoring the diversity among all people.

- Families make the best choices when they have comprehensive information about the full range of formal and natural resources in their communities.

- Creative, flexible and collaborative approaches to services allow for individual child, family, and community differences.

When the council issued requests for funding, they translated these values and stated that proposals would be funded which

- use natural settings as the primary location for providing services and supports;

- provide options for families in terms of the types of services and supports to be rendered;
- develop with families Individualized Family Services Plans (IFSP) that reflect more than just the services and supports available through the providing agency;
- demonstrate service coordination will occur across agency lines;
- demonstrate innovative ways to use current funding to access generic services; and
- demonstrate linkages with informal supports.

Research findings related to these issues were presented and future directions were discussed. *(Presenter abstract)*

SPEAKER: **John Nackashi, PhD, MD**
Associate Professor, Medical Director
Pediatric Care Coordination Program and Pediatric Home Care
University of Florida and American Academy of Pediatrics
Committee on Children with Disabilities

Who Are The Children?

The health care needs of children have changed dramatically in recent years. Due to advancements in medicine and technology there is a growing population of children with special health care needs (CSHCN) who require skilled health care and complicated equipment on a long term basis. These young children typically require early intervention and educational programs, special therapies, transportation, and nursing services.

Definitions and estimates of childhood chronic conditions vary. Jessop and Stein (1988) define childhood chronic conditions as lasting three months or more in one year, or requiring at least one month of hospitalization. Recent estimates (The Future of Children, 1992; Newacheck & Taylor, 1992) on childhood chronic illness prevalence and severity indicate that 31 percent of children are affected by chronic conditions. Among these children are many highly prevalent conditions and include very mild conditions such as respiratory allergies and ear infections to moderate and more significant conditions like spina bifida and diabetes. Of this 31 percent, 13 percent have activity limitations which affect their daily life. Of the total number of children with chronic health care conditions, 5 percent have severe conditions accounting for 19 percent of physician contacts and 33 percent of hospital days related to chronic illness. Other investigators (Boyle, Decoufle', Yeargin-Allsopp, 1994) have found that 17 percent of children in the United States were reported to have had a developmental disability. The prevalence of the individual disabilities range from 0.2 percent for cerebral palsy to 6.5 percent for learning disabilities. These conditions taken together had a substantial impact on health and educational function of effected children: 1.5 more doctor visits, 3.5 times more hospital days, twice the number of school days lost, and 2.5-fold increase in a likelihood of repeating a grade in school compared with children without these conditions. The extent of this impact was much greater for those children with cerebral palsy, epilepsy or seizures, delays in growth and development, or emotional and behavioral problems.

While the incidence of childhood disorders has remained relatively stable for the past 20 years, the survival rate of children have improved greatly. In addition, new clusters of childhood chronic conditions are emerging. These categories include infants surviving very low birth weights, children with Human Immunodeficiency virus (HIV) or Acquired Immunodeficiency Syndrome (AIDS), and children with immune suppression following organ transplantation. The development of medical specializations has improved the ability to diagnose and treat, resulting in improved life expectancy of these children. In 1900, mortality rates for children, 1-14 years, were 870 per 100,000 children. In 1987, the mortality rate was 33 per 100,000 children. This trend demonstrates progressive improvements in survival rates in children but there has not been a concomitant drop in the prevalence of childhood chronic illnesses and disabilities.

A Continuum of Care

Advances in medicine and technology have improved the survival rate and outcome of children with chronic illness and developmental disabilities. Consequently a continuum of options (Reiss, Nackashi, Siderits, 1990) for delivering needed services for these children needs to be expanded significantly because changes in the systems to provide health care and education have not kept up with the advances in medicine. In addition, public laws mandating developmental intervention and educational services for children are relatively new. Prior to P.L. 94-142, many children were not receiving developmental and educational services.

The goal of the continuum of care, in addressing the needs of these children, should be to

- enhance the quality of care to children whether or not the child has an optimistic prognosis;
- minimize the consequences of the child's biological disorders;
- foster the child's growth and development;
- assist the child to develop his/her full potential; and
- diminish negative social and behavioral consequences for the child and family.

The goals of the continuum of care in addressing the needs of the family, should be to

- support the family in fostering the child's sense of belonging to a family unit;
- provide the family with the knowledge, skills and services needed to meet the child's medical, development, educational and emotional needs;

- support the family in its roll as primary caretaker;
- address the emotional and adjustment needs of the family members regarding the child with a special health care need and his/her place in the family;
- foster the independence and competency of the family;
- support the family in its decisions regarding the care of the child; and
- educate service providers from all involved disciplines regarding the needs and strengths of families and the role and responsibilities of the service system.

In order to successfully achieve these family-centered and system-focused goals, a community-based continuum of care is needed that is integrated, care-coordinated, flexible, and family-centered. This continuum should integrate health care needs with educational and developmental considerations. This continuum should also allow the child to readily move between and among components as needed, and should allow for open communication and coordination among service providers and family members throughout the time the child is in need of special services.

Inclusion Requires Collaboration and an Enabling View of CSHCN

Meeting the challenge of inclusion of children with special health care needs requires a continuum of care. This continuum of services introduces significant and challenging opportunities. Professionals must learn to communicate and collaborate with each other in an interdisciplinary manner. Physicians need to become focused more on appropriate childhood functional outcomes rather than on the acute medical needs. The acute medical model is described as a deficit model ("rule out" what could result in negative consequences) and must be replaced by a system that evaluates the total child medically, developmentally, and psychosocially. There must be a greater understanding of strengths as well as the need to detect needs. At the same time health care providers need to view children in an enabling context stressing the abilities and competency of young children with special health care needs rather than their perceived handicapping condition. *(Presenter paper)*

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SPEAKER: **Victoria Hertel, RN, MS**
National Association of State School Nurse Consultants
Colorado Department of Health & Colorado Department of Education

School Health Services

Schools are required to provide *health* services *not medical services* in the school setting for the 3 to 21 year olds who have health problems that significantly impact their ability to learn. When providing this health care in the schools, the state medical and nurse practice acts must be reviewed to identify what services or procedures require a license. If school personnel are providing these services, are they practicing medicine or nursing without a license? Can school personnel be held responsible for doing so, if the parent asks for the care to be done in the school setting? Which procedures require a license to do? What is an invasive procedure?

Start by looking at the medical and nurse practice acts in the state where the child is in school. Some states allow the registered nurse to delegate, train and supervise persons to give care for which a license is required *under certain circumstances*. Other states do not. Colorado used to be one of those states that did not. The medical practice act regulates medical practice that can be delegated to the registered nurse and to unlicensed persons if the physician is onsite. The invasive procedures are usually the ones for which a license is required. If school personnel provide health service that requires a license, they are still held responsible even if the parent requests them to do so. A school registered nurse needs to be involved to assess the child's health needs in the school setting, and to determine the type of health care to be given and by what school personnel. There are times when the health care can only be safely provided by a licensed person.

The school registered nurse's role also includes the development of a health care plan for the school setting. This is to be done in cooperation with the parents, the student when appropriate, the school administrator, and the health care provider. This health care plan is part of the health assessment and then becomes part of the Individual Family Service Plan (IFSP) or the Individual Educational Plan (IEP). The health care plan should be in the staffing folder. If the child is in regular education, the health care plan should be in the child's individual health record. *(Presenter abstract)*

SPEAKER: **Marjorie Long, JD**
Attorney at Law, Legal Consultant

Basic Civics Review: Branches of Government and Their Respective Functions

Legislative - makes the laws (statutes), amends laws

Executive - carries out the laws made by the legislative body (regulations)

Judicial - interprets the laws, whether made by legislature (statutes and constitution) or by executive/administrative body of government (executive orders and regulations)

Nurse Practice Acts, like all legislation concerning licensed professionals serving the public, are passed to define the practice of nursing and to protect the public.

With input from various sources (e.g., the State Board of Nursing, School of Nursing, professional nursing groups), the legislature drafted the original Nurse Practice Act and has made changes (amendments) to it over the years. The state has an interest in protecting its citizens from unscrupulous or improperly trained professionals, be they nurses, doctors, lawyers, dentists, or realtors. Thus each state sets forth in its statutes or laws what the licensing requirements are, what constitutes the practice of a specific profession, etc. State statutes regarding professional practice are usually broadly written.

It is the responsibility of the executive branch, through administrative agencies, to carry out the laws as passed by the legislature. State administrative agencies, such as the Board of Nursing, are charged with promulgating regulations which describe how, when, where, and to what extent the legislative mandate is to be carried out. Regulations, in contrast to statutes, are narrowly written and provide specific guidance for implementing the law.

Because regulations are generated and implemented by a state agency's administrative board, regulations can be passed or amended more quickly than statutes, which require majority votes following sometimes extensive committee discussions and modifications before passage. A state agency is in a better position to define the particulars of how a statute should be implemented because its existence is based upon a level of knowledge and experience on a specific subject usually not found among the members of a general legislative body. For example, the Board of Nursing is better able to define invasive procedures than is the legislature.

Some state Nurse Practice Acts provide little guidance in the statute itself, but excellent guidance in the regulations. Other states have very extensive language in the Nurse Practice Act regarding a variety of permitted as well as proscribed (or prohibited) activities. Because of the differences between state legislatures, the varying economic and political "cultures" between states, and the needs of the citizens, there is no one model for a successful Nurse Practice Act and accompanying regulations. For these reasons, it is important to understand the political process in your home state and to work toward a marriage of that process with the goals identified under implementation of IDEA as related to invasive procedures.

Although a school nurse may legally delegate nursing tasks to other trained personnel, the nurse still retains responsibility and liability should problems arise in the performance of delegated procedures. It is essential that the nurse make the judgment as to whether a particular child can be safely served by a trained, nonmedical person or whether the child's condition is such that the services must be provided by a licensed nurse. School administrators and teachers are not trained to make such health care decisions.

The Individuals with Disabilities Education Act (IDEA) is a federal law with which states must comply in order to obtain federal funding for public education. In the past, many state Nurse Practice Acts have contained, either by omission or by proscription, language which hindered state compliance with IDEA. The goal of this national conference is to provide technical assistance, policy analysis, and support to attendees so that they can return to their states and effect those particular changes necessary in order to be safely in compliance with the federal mandates under IDEA. *(Presenter paper)*

SPEAKER: **Mary Hicks**
Parent Advocate

One Family's Experience with Inclusion

Mary Hicks' is the mother of a three year old girl with multiple medical problems who is currently reliant on gastrostomy feeding due to oral hypersensitivity. After two years of family home care, the Hickses found few choices available for day care since many providers were uncomfortable with the G tube feedings that are a part of daily life for the family. Therefore, their daughter was initially enrolled in a non-inclusive day care setting.

Shortly after the initial placement, the Hickses enrolled their daughter, still at age two, at the JFK Child Development Center (then known as the federally funded IDEAL Child Center, a model inclusive child care program for children from age six weeks to three years). JFK is a University of Colorado Affiliated Program providing mandated services under the Federal Administration for Developmental Disabilities. Its services include training, exemplary programs, and research for the benefit of people with developmental disabilities and their families. Assisted by Dalice Hertzberg, Nursing Consultant to the JFK Child Care Center, Mrs. Hicks' daughter was moved to an inclusive day care program.

Over a period of about two weeks prior to entry to JFK, a complete Health Care Plan was developed by the nurse, the parents, the child's physician, and the Center Director. Consistent with professional standards, aspects of the family's tube feeding methods were incorporated into procedures at the Center to best meet the child's needs. Parent opinions and decisions were sought in implementing the plan as well. Keeping communication open, the nurse quickly learned a great deal from the Hickses' perspective (e.g., their need to be informed of even the slightest change in implementation).

Until enactment of the Delegatory Clause of the Colorado Nurse Practice Act, Ms. Hertzberg provided the tube feedings. Once the Act was amended, three paraprofessionals were prepared to provide the procedure. The nurse was experienced in paraprofessional training and had access to a State-approved training manual and a training video to structure the teaching of content and skills. The paraprofessionals observed the nurse until they were comfortable with the procedure. They then completed a written test on content and skills, and performed the task while observed by the nurse. Once they felt confident in their skills, they were rated by the nurse on a Behavior Skills Test. Upon successful completion of the Skills Test, a certificate was awarded that is maintained in the paraprofessionals' personnel files attesting to their competence to perform the trained procedure for the designated child in that setting.

Staff rotate performance of the procedure so that their skills do not deteriorate. The nurse regularly follows up with the fully trained paraprofessionals at least once a month, in principal. In practice,communication of progress and problems occurs much more frequently as issues arise.

The paraprofessionals immediately and fully integrated the tube feedings into the school environment. The tables were moved closer and Mrs. Hick's daughter is seated with the other children. The paraprofessional sits to the child's side serving her needs with one gloved hand while meeting other children's needs with the other hand. The difference between the nursing focus on individual care and the education emphasis on group care is a paradigm shift that benefits the children and enhances the paraprofessional inclusion skills.

Mrs. Hicks reported that the presence of other children has stimulated her daughter's interest in oral ingestion of food. Now her daughter will occasionally allow other children put food in her mouth. Mrs. Hicks has noted other benefits for her daughter as well owing to placement in an inclusive setting. *(Staff Summary of presentation and staff interview of Dalice Hertzberg, RN, MSN, CRRN; Nursing Consultant; JFK Child Care Center)*

Open Discussion

1. **Q:** Did any Colorado school districts have no school nurses whatever?

   A: Colorado State law mandates an RN in every administrative unit for special education. So, it was a compliance issue. (*Hertel*)

2. **Q:** What values underpin Colorado funding guidelines?

   A: Projects are funded when:

   - They provide a natural setting for services
   - Families are provided with options
   - The Individual Family Service Plan (IFSP) reflects multi-agency collaboration in provision of services
   - Services are coordinated
   - An innovative use of existing generic services is demonstrated
   - Informal supports are provided to the family. (*McNulty*)

3. **Q:** What evaluation plan is in place to assess the impact of delegation impact on children?

   A: No systematic program evaluation is in place. (*Hertel*)

   R: As an administrator in a school system, compliance with reporting for systematic evaluation would be burdensome although the assessment of effectiveness would be valuable (*Comment from floor*).

   R: It is standard policy to investigate excessive absences for any child. Also, the individual nurse reviews and monitors implementation for individual children (*Comment from floor by M. Swigert*).

4. **Q:** What is the family's role in delegation?

   A: Parents are a vital part of the health care plan - planning process is collaboration of the parent, school nurse, school administrator child (if age appropriate), and the child's physician (*Hertel*).

5. **Q:** What about objections to delegation?

   A: If parent objects, dependent upon the specifics of the situation, the parent may need to pay for nursing services if others agree that delegation can be safely accomplished (*Hertel*).

   A: Disagreement can be mediated through a due process hearing (*Long*).

6. **Q:** What is the current status of the issues of inclusion, family-centered care and delegation of nursing tasks in medical education?

   A: These issues still receive limited attention although there is a growing emphasis. Attempts are underway to educate physicians regarding the needs of children with special health care needs. Some of the issues are also beginning to appear in some residency training programs (*Nackashi*).

7. **Q:** In the education of physicians in inclusion?

   A: Little or none. More emphasis is being placed in practice. The American Academy of Pediatrics is planning to do a four year project to educate practicing MDs about children with special health care needs (*Nackashi*).

QUALITY OF CARE:
The Structure that Allows for Safe and Legal Delegation

MODERATOR: Wendy Nehring, RN, PhD
AAMR Past Nursing President

SPEAKER: **Betty Presler, RN, PhD**
Faculty of the University of Kentucky College of Nursing and
Committee on National Standards of Nursing Practice, Early Intervention

What Does Nursing Bring to the Care of Children with Special Health and Developmental Needs in Schools and Early Intervention Settings?

Nurses' education and experience with health promotion, disease prevention and health-problem management within an interdisciplinary, family-centered, developmentally appropriate framework make them a valuable resource in the provision of care to all children served in educational settings. Nursing is defined as the diagnosis and treatment or human responses to *health* and illnesses (ANA, 1987). Specifically the role of the nurse providing care for infants, toddlers, and adolescents with special health and developmental needs and their families can include

- prevention of health and developmental problems through risk analysis and reduction strategies targeted at individual, family or community levels;
- early identification of potential or actual problems at individual, family or community levels;
- comprehensive nursing assessment of the individual's, family's or the community's pattern of health;
- integration of nursing assessment and interventions into the individual's, family's or community's plan of care;
- provision of individual or population-based nursing interventions;
- delegation of selected nursing interventions with responsibility for ongoing training and supervision of the care provider and monitoring and evaluation of the quality of care provided and effect on health status outcomes; and
- collaboration with other health professionals and the family to provide individual or population-based services.

Evaluation of the quality and effectiveness of individual or population-based care. (Consensus Committee, 1994).

These components of the nursing role can be defined as health promoting, health supporting and health restoring (ANA, 1994). Health promoting practices encourage health patterns of living, foster development and support the priorities of children and families. Supportive practices foster the development of new behaviors or modify existing behavioral or environmental stressors that could interfere with optimum health and development. Restorative practices modify or reduce the negative impact of illness or developmental disability on the child and family and include health problem management.

This description of nursing is intended to underscore the importance of including nursing as a service provided to *all* children in *all* educational settings today the opportunity to recruit and hire large numbers of nurses has never been greater. Restructuring and down-sizing of costly hospital-based health services as the health care system shifts emphasis from tertiary to primary health care is creating an exodus of highly-skilled nurses from hospitals. Many of these nurses could be employed to develop and provide quality, cost-effective care services to children in schools or other educational settings.

What is the Purpose of *Standards*?

The purpose of the *National Standards of Nursing Practice for Children with Special Health and Developmental Needs* is to fulfill the profession's obligation to characterize and measure quality care (ANA, 1993). They can and should be used by nurses, consumers (families), and administrators of agencies that provide services to children with special health and developmental needs. Administrators can use standards to develop job descriptions, policies, procedures and systems of evaluation. Nurses can use the standards to guide and measure their practice. Consumers can use standards to measure the quality and practice of an individual nurse or the quality of nursing care available in agencies such as hospitals, schools and child care centers.

How are the *National Standards* Organized?

The *National Standards* identify structure and process criteria that describe and measure quality. Structure standards describe the agency's responsibility to provide an environment and resources that support quality care. Agencies that do not support quality care through provision of adequate resources to include staff, training and evaluation are accountable for the poor outcomes that may result. Process outcomes describe what the nurse does as a care provider (Standards of Care), and as a professional (Standards of Professional Performance). Each have specific measurement criteria which further describes each standard. Outcome standards are not included because they must be individualized for each child and family and reflected in an individualized plan of care such as the Individualized Family Support Plan (IFSP) or the Individualized Educational Plan (IEP).

Do the *Standards* Help With the Issue of Delegation?

A framework for safe delegation is supported by the *National Standards of Nursing Practice for Children with Special Health and Developmental Needs*. First, every child who requires a nursing intervention must have a thorough nursing assessment. Second, each child's health needs/problems should be included in the IFSP or IEP and goals/outcomes identified with specific evaluation criteria. Third, a nurse can delegate selected nursing interventions based on criteria outlined in their state nurse practice act. Colorado's Nurse Practice Act is an excellent model. However, a nurse does not delegate responsibility for ongoing assessment of the child's health status, identification of appropriate health related outcomes, developing nursing and/or health components of the child's plan of care and evaluating both the quality of the delegatee's intervention and the effect of the intervention on the child's health status. Fourth, nurses, in collaboration with administrators, are strongly encouraged to develop a "systems approach" to monitor and evaluate the effects of delegation on health status outcomes of individuals or groups of children.

Without a systems approach to evaluation how can nurses or educators ultimately know *if* in their efforts to support inclusion of children with special health needs they are creating an unsafe environment for selected children who must rely on the technical care of an unlicensed delegatee?

How Can I Use These *Standards* in My School or System?

First, there has to be a vision of what is possible and the motivation to transform that vision into reality for all children in educational settings.

Second, school administrators, teachers, nurses, and other health professionals must translate the vision into a system of education which supports health for all children and the inclusion of children with special health care needs. This system would include the structural supports described in the *Standards* such as adequate, well-trained staff and resource 5.

Third, *National Standards* can be adapted as needed to focus more specifically on the needs of the children and families served by a specific educational agency. These adapted standards can then be translated into policies, procedures and protocols which define, describe and operationalize quality care.

Fourth, a monitoring and evaluation system should be developed which goes beyond the individual focus of the IFSP or IEP. The question is: How is our system of care affecting the children we serve--positively or negatively? Is health promotion changing attitudes or behaviors related to specific issues/problems? Does health support decrease illness-related absences in high risk groups such as children with asthma or with spina bifida? Does delegation of selected nursing interventions to non-professional care givers increase the risk status of the child and the liability of the school system?

Where Can I Get Help?

Members of the ANA Consensus Committee and/or national and state leaders in ANA and state affiliates are available to help. In addition, many states have a State School Nurse Consultant hired by the Department of Education or the Maternal-Child Health Bureau (or similar state agency). All states have a program or system designed to ensure services for children with special health care needs (Title V CSHCN Programs). These programs usually employ nurse leaders who have state-wide responsibility who could either directly help or refer you to other nurse leaders in your county or district. Also, most states have an active School Nurse Association with many capable leaders. Last, but certainly not least, the University of Colorado School Nurse Practitioner Program and this project are other resources. Judy Igoe and Marilyn Krajicek know many of the nurse leaders who could provide assistance in each state.

Nurses are committed to promoting and supporting the health of all children. Nurses support inclusion and want to ensure that children with complex health problems participate in educational programs and receive safe and effective care. Nurses want to enter into partnership with families and school officials and be involved in developing quality health care programs and services for all children to include children with special health and developmental needs. Let's work together to make the vision a reality. ***(Presenter paper)***

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SPEAKER: **Victoria Hertel, RN, MS**
National Association of State School Nurse Consultants
Colorado Department of Health & Colorado Department of Education

Statewide Focus

In Colorado, there is a Child Find Process to be in place in each administrative unit to identify those children birth to five years who have potential developmental or other health problems that could affect their ability to learn. This is to be a community based interdisciplinary team. If the child is 3 to 5 years old the school is responsible to provide services for the child in the least restrictive environment. The Colorado Department of Health (CDH) and the Colorado Department of Education(CDE) developed and printed *Procedure Guidelines for Health Care of Special Needs Students in the School Setting* as a standard of practice and care guide for all children and youth in the school setting.

In that manual, there is a "Technical Assistance Skills Chart" to identify school personnel who can appropriately provide each type of care in the school setting. This care is based upon a health care plan developed for the child. This plan then becomes part of the IFSP or the IEP. It is recommended for this health care plan to contain the following components:

- identifying data
- source of medical care
- health problems list
- description of illness/condition
- special precautions
- health care treatment plan
    - schedule
    - personnel trained
    - procedure
    - physician written authorization
- emergency information
    - person(s) to contact
    - back-up plan
- transportation health needs plan
- re-evaluation

The plan is developed by the parent, the student if applicable, the school nurse, the school administrator and the health care provider. The school registered nurse is responsible for implementation of the plan and determining if the health care procedure can be delegated.

Numerous regional workshops were held around the state on the purpose and development of a health care plan and to inform the school nurses of the Delegatory Clause in the Nurse Practice Act. This included their role and responsibility in delegation of care and stressed that if they determine the health care can only be safely provided by a licensed person, it is not to be delegated. Presentations were also made at the special education directors' meetings on the delegation of care. Each year there is a session on both topics at the statewide school nurse conference. These workshops and the statewide conference are funded by the CDE Special Education Services Unit.

The same requirements for health care plans and delegation of care are in place in rural areas as in urban areas. Each administrative unit of special education is required by state law to have an appropriate number of school registered nurses for the special education program. *(Presenter paper)*

SPEAKER: **Patricia Motz, EdD, RN**
Consultant, Employee Health Services, Denver Public Schools

Delegation in the Denver Public Schools

Historical Overview -- Students With Special Needs

Prior to 1976, students with special needs were served in community center settings, institutions, hospitals, private homes, special school settings, and other alternate placements. It is important to note that some children had absolutely no service and were kept at home or "hidden away" and therefore, unknown to the public schools and other placement agencies. With the passage of the P.L. 94-142/Individuals With Disabilities Education Act (I.D.E.A.) in

1975 (subsequently amended and renamed IDEA in 1990), public schools and other settings were given the opportunity and challenge to serve **all** children regardless of handicapping condition or level of mental functioning.

From 1976 through 1988, I was very fortunate to serve on a multidisciplinary team as a school nurse practitioner for the Department of Special Education in the Denver Public Schools. This team was responsible for evaluating all students in Denver County, ages 5-21 years, who were eligible for services in the public school setting as a result of IDEA. As a result of performing thousands of evaluations, children and adolescents were identified for services who ranged from being severely disabled, trainably mentally handicapped, emotionally disturbed, physically handicapped, moderately mentally handicapped, gifted or any combination of the aforementioned. There were parents/guardians who wanted all services for their children in the child care/public school settings and those who sought legal assistance to keep their children in "protective" placements in the community or at home.

In order for these children to be served in the "most appropriate- least restrictive placements (P.L. 94-142)," a staffing was held with the parent/guardian, multidisciplinary evaluators, and appropriate administrators. This was done in order to develop the Individualized Educational Plan (IEP). Currently the IEP is done on children ages 3 years to 21 yrs. The Individual Family Service Plan (IFSP) is developed by the parent/guardian and multidisciplinary staff for children ages birth to two years. This plan is more family-centered, while the IEP is more student-centered, as it is commonly done in an educational setting.

At this conference, we are discussing those children with special needs that have been identified as having invasive procedures, i.e., urinary catheterization, colostomy/ileostomy care, gastrostomy feedings. At the inception of this program in the Denver Public Schools in 1976, the parent/guardian of a child with this type of procedure needing to be performed during the school day would demonstrate the required procedure to the school staff in the manner in which it was being done at the child's biological/ foster home, group home/community or hospital setting. The State of Colorado did not have a "delegatory" clause in the Nurse Practice Act and therefore, the school nurse was not allowed to train, supervise, delegate, or evaluate the above-mentioned procedures. Many of these procedures became the responsibility of the classroom paraprofessionals (paras). These paras were told by the staff that this function was part of their "duties", or they volunteered to do it because they wanted to take care of the children whatever their special needs (i.e., diapering, feeding, lifting, changing menstrual pads, catheterizing). It should be noted that many of these paras performed the tasks responsibly. The special education teacher and the school nurse had responsibility for observing these functions and, hopefully, making sure they were done with the best interests of the child in mind.

Grievance Procedure Filed
by the Denver Federation of Paraprofessionals

In 1992, the paraprofessionals working in the classrooms where children with special needs were being served filed a grievance with the Denver Public Schools. This was done in order to seek training, guidance, evaluation, reimbursement, and legal clarification for the performance of these designated services. As a result of the grievance, a committee was formed and a training packet and program were put together over a one year period, not only for the paras but also for the school nurses who would be involved with these children (see sample packet in Appendix). In the Denver Public Schools, the paras are currently given a stipend ranging from $50 to $100 per month depending on the number of procedures they perform. Paras are encouraged to attend a pre-training inservice where they obtain an overview of what may be involved in the performance of these procedures. They have the opportunity to view training videos and review the training packets. There is also a question-answer session. The para makes a personal decision as to whether or not to accept this responsibility. If the para decides to go further with this process, it is then that the para and the school nurse continue with the training, supervising, monitoring, and evaluation of the designated procedure(s) on site with the student(s). The Health Care Plan is reviewed at this time (see below). The grievance helped us to explore together how we could strengthen and enhance our roles in the delivery of specialized services for children. It instilled in all of us a desire for role change, role modification and accountability in meeting the needs of children.

Colorado Nurse Practice Act -- Delegatory Clause

Following the efforts of many individuals, the Colorado Nurse Practice Act was changed in 1992, to allow nurses in child care, school, and other settings to train, supervise, delegate, monitor, and evaluate these specialized procedures with non-licensed personnel. It is the nurse who is the vital link to the health and to the education of these children. We are providing unique nursing health services to children, youth, parents, staff, and the community in the school setting. This is a model of teamwork -- parents, educators,legislators, health providers, and others -- truly working together as child advocates!

Health Care Plan

Probably the most important part of the IFSP and the IEP is the Health Care Plan (see sample in Appendix). This plan is developed and signed by the child's primary medical care provider, the parent/guardian, the nurse and the administrator in charge. Anyone who is caring for the child with any special needs must have access to this plan. It is the nurse's responsibility to be in charge of the plan and to keep it current. The nurse is delegating the task and procedure but *not the professional nursing judgement and responsibilities. Any task or procedure that is delegated to a non-nursing personnel must be performed in a safe and legal manner.*

Ingredients for Success

The number one ingredient is communication--both written and verbal. The responsible nurse needs to keep close contact with the parent/guardian, doctor(s), legislators, administrator(s), educational staff (including the paraprofessionals), other nurses and community resources. This is a *multidisciplinary* team effort of all interested persons working together on behalf of the children and their families. *(Presenter paper)*

SPEAKER: **Rethea Fordyce**
President, Denver Federation of Paraprofessionals

Delegation: A Paraprofessional Perspective

In 1992, a grievance was filed with the Denver Public Schools on behalf of the Denver Federation of Paraprofessionals. The grievance addressed performance of invasive procedures for school children with special health care needs. As a consequence of an open-ended clause in job descriptions, paraprofessionals could be called upon to perform any assigned task not otherwise specified. Responsibility for invasive procedures fell to the paraprofessional under this catchall.

Paraprofessionals were hired with minimal skill requirements and were expected to learn needed skills on the job, including skills to perform invasive procedures. Thus, they were essentially untrained for responsibilities they regarded as exceeding reasonable expectations for their positions. Refusal of the responsibilities risked termination. Nor was acceptance of the responsibilities acknowledged by additional compensation. In addition, at the time, paraprofessionals were performing the procedures in violation of the Colorado Nurse Practice Act since it included no provisions for delegation of nursing activities to unlicensed personnel.

Thus, the paraprofessionals were aggrieved on several grounds. These included

- lack of preparation for the responsibilities;
- absence of choice to accept or reject the responsibilities;
- illegal nature of delegation of nursing tasks;
- failure to compensate for additional work; and
- exposure to personal liability.

The grievance process resulted in establishment of a task force to address the constellation of issues associated with performance of invasive procedures. The task force agenda included

- need for paraprofessional training;
- paraprofessional choice;
- status of the Colorado Nurse Practice Act;
- liability; and
- compensation.

The task force was characterized as a cooperative effort in which all parties were strongly motivated to resolve the issues.

Actions taken by the Denver Public Schools in response to the recommendations of the task force included provision of initial and ongoing training regarding invasive procedures, voluntary participation, monthly stipends based on the number of procedures performed, and paraprofessional input to planning and documentation for individual children. In addition, while the task force was convened, the Colorado Nurse Practice Act was amended to allow for safe and legal delegation of nursing activities to unlicensed personnel. The paraprofessionals determined that sufficient clarification and resolution was achieved to withdraw the grievance, although the issue of paraprofessionals' risk of personal liability remains under study.

It is the paraprofessional perspective that invasive procedures require very specific task training for which on-site demonstrations are often too short to be thoroughly comprehended, to formulate questions, and to rehearse skills. The need for practice under supervision was stressed. In addition, paraprofessionals wish to be included as a part of the education-health planning team. To safely perform invasive procedures, they need access to the child's history and awareness of the child's needs. They also deserve legal information including personal liability incurred when accepting responsibility for invasive procedures, as well as respect for their contributions. Finally, invasive procedures exceed reasonable expectations for paraprofessionals, legitimizing both choice and stipends. *(Staff Summary)*

Open Discussion

1. **Q:** What is the status of medication administration?

A: In Colorado, the Board of Health requires written parent permission, and physician authorization for dispensing medication. The medication must be in a pharmacy-labelled bottle. A log of administration must be kept, and secure storage of medications must be provided. Procedures must be documented for dispensing controlled substances such as Ritalin. *(Hertel)*

A: In practice, the secretary often administers meds. The system needs more structure. The more people involved, the greater the risk. *(Fordyce)*

A: In special education settings, the special ed. teacher gives medications. In regular schools, secretarial unions are beginning to protest as did the paras.*(Motz)*

R: The scope of the medication administration problems is very large in large school districts. *(Comment from floor)*

R: In New York there is no delegation occurring. There are 3000 school nurses. Medication can be administered by non-nurses, but the child must be self-directed (i.e., understand own meds). Where a child is cognitively impaired, delegation is not permitted. When districts were informed of the implications of cutting nurse positions, most chose not to do so. *(Comment from floor)*

2. **Q:** How do you address a parent's non-standard administration of a procedure, particularly as it relates to trust in the relationship?

A: If there is a disputed issue, the nurse may always request a second opinion. It is a right and a responsibility. *(Hertel)*

A: To ensure good communications with the parent, it is advisable to send a copy to the parent of material provided to the physician and to notify the parent of how the procedure will be done at school. Trust and cooperation are maintained by expressing the attitude that we are all working together for the benefit of the child. *(Motz)*

R: Regarding absences of persons designated in the plan for invasive procedures, under the Colorado Nurse Practice Act, it is the nurse's responsibility to ensure that prepared back-ups are designated and available. *(Comment from floor)*

LUNCHEON SPEAKERS

MODERATOR: Marilyn Krajicek, EdD, RN, FAAN

SPEAKER: **Sally Phillips, RN, PhD**
Associate Dean, University of Colorado School of Nursing

Report from the National Council of State Boards of Nursing

Dr. Phillips reported on the status of delegation issues as reviewed at the National Council of State Boards of Nursing. Coincidental with the session was the National Council's vote on a model Nurse Practice Act. The Act will illustrate model language and major issues for practice.

Delegation is extensively addressed in the version about to be adopted. Delegation can be effective when nurse is in the pivotal role to delegate with accompanying documentation and evaluation. Many states are writing Letters of Declaration to clarify nursing delegation. *(Staff summary)*

SPEAKER: **The Honorable Patricia Schroeder**
Congressional First District

The Future of Health Care

Representative Schroeder reported the status of health care reform discussion in Washington at the time of the conference. With the cancellation of the Congressional Recess of August, 1994, a major effort was underway to enact health care reform legislation based upon the Gephardt (House), the Mitchell (Senate) bills, or anticipated Republican alternatives.

The Gephardt bill was described as retaining maximal consumer choice. It defined Medicare Part C as a coverage option for small employers and offered choices for part-time and low wage workers. Employer contributions would be mandated, with subsidies available for smaller firms. Larger corporate employers would contribute 80 percent of coverage costs. Low income families would be eligible for subsidies for their 20 percent contribution. Long term care and mental health coverage were also addressed in the Gephardt bill. Automation and standardized reporting would maximize administrative efficiency.

In contrast, the Mitchell bill required employers to contribute only 50 percent of coverage costs. Many important issues, such as the needs of part-time and low wage workers, were not clearly addressed in the Mitchell bill. Nonetheless, passage of either the Gephardt or Mitchell bills was expected to yield a mandated package of basic benefits that would serve as a platform for additional consumer choices.

Technological advances currently in use in pilot projects and in military medical services were also described. The shared theme of these advances was reliance on telecommunications facilitating functions as diverse as patient evacuation, long distance triage and expert consultation, and remote monitoring of patient status. These developments are indicative of the potential of technology to increase accessibility of care and to reduce costs. Such advances stand in sharp contrast to the late 19th century service delivery model underpinning current health care policies.

ISSUES IN SPECIAL EDUCATION: Inclusion

MODERATOR: Fred Smokoski, EdD

SPEAKER: **Kathleen Brendza**, *Administrator*
The Center
Leadville, Colorado

A Model Program for Inclusion

The Center is a rural, community-based, family-centered model program of the Lake County School District. It is a pre- and after-school inclusive program serving infants to teens, and their families in Leadville, Colorado.

The Center has been recognized by Yale University as one of the "Schools of the 21st Century", and by Harvard University as a national, exemplary family center. Additional awards include the El Pomar Award for Excellence, the U.S. West Jack MaCallister Award, and the Colorado Trust Award for Excellence, as well as recognition as the Most Outstanding Advocacy Organization in Colorado by the Colorado Child Protection Council. The *Brokaw Report* and PBS aired television programs featuring The Center as well.

A film segment was presented from a television special report, *The Brokaw Report, America's Schools: Pass or Fail?*, that demonstrated inclusion as implemented at The Center. The film highlighted holistic, interdisciplinary early intervention in the preschool setting. Key elements were: inclusion, individual service planning, parental support services and participation in planning and monitoring of care, respect for cultural diversity, and utilization of existing generic services to address child and family needs. *(Staff summary)*

SPEAKER: **David Stockford**
President, National Association of State Directors of Special Education
Director, Division of Special Services, Maine Department of Education

The Role of Special Education in Inclusion

The National Association of State Directors of Special Education (NASDSE), in *Leading and Managing for Performance: An Examination of Challenges Confronting Special Education*, recognizes the significant contribution special education has made and the leadership role special education must play with local, state and national efforts to reform education. It recognizes this as a time for serious reflection, action, and collaboration in the context of school reform and special education. Emphasis is placed on changing from an input system to a performance-based system, and NASDSE is committed to providing leadership in collaboration with all other significant educational and human services organizations in the implementation of responsible reform.

Three of NASDSE's national initiatives and strategies are pertinent to our discussion:

1. prevention/early intervention
2. inclusive schools
3. school-based/school-linked health and social services

Key to the present debate around "inclusion" is NASDSE's definition of special education as "a system of options provided to a student with disabilities to assist the student in meeting performance standards based on high expectations." NASDSE has identified that one of the changes which is required includes thinking of special education as a service, rather than a place.

Special education should, in addition to ensuring appropriate learning environments, provide other support services to students and families in conjunction with other agencies that are required to participate in providing the least restrictive environment for a student with disabilities.

Special education should also interface with services provided to students and their families by other agencies. Special educators must promote collaborative intra- and inter-agency relationships, broad-based community support, collective responsibility for learning, advocacy for students and families, comprehensively prepared personnel, and a de-centralized system of services where decisions are made, jointly by professionals, parents, and when appropriate, students.

Two very important challenges that face special education are protection of students with disabilities through the application of basic procedural safeguards and also through data-based decision making. More effective methods need to be used which yield effective and rapid resolution of issues for the future.

While the basic standards of law create the framework for full participation, the provision of Free Appropriate Public Education will guide the principles in making decisions about the new system of education. Changing conditions and challenges of new at-risk populations require that we develop public policy in collaboration with representatives of other service agencies to insure that standards developed in isolation do not become barriers to comprehensive services for children and parents. Schools have, and will continue to have, significant impact. Restructuring will provide for more responsive programs and service. *(Presenter abstract)*

SPEAKER: **Fred Smokoski, EdD**
Director, Special Education Services Unit
Colorado Department of Education

Implementing Inclusion: A Statewide Perspective

Part H of the Individuals with Disabilities Education Act deals with children with disabilities who are aged birth to three and approaches their education in a somewhat different manner than the population of students who are five through 21.

In the National Association of State Directors of Special Education (NASDSE) publication, *Leading and Managing for Performance: An Examination of Challenges Confronting Special Education*, several strategies and initiatives are outlined. Pertinent to today's meeting are those which deal with early intervention, inclusion, school based health needs and parental involvement.

The State of Colorado has been a leader nationally in those four initiatives. Colorado was among the first states to be awarded both planning and implementation grants in the area of early childhood education and the study conducted here has been used by other states to obtain funding for early childhood programs. It also was among the leaders in obtaining grants for the education of children from birth to three.

Inclusion, a very strong Colorado effort as evidenced by the over 1,400 people who annually attend our inclusion conference, is looked on differently by the people who work with the population of students birth to three. Inclusion for school aged youngsters means that a child is educated in his home school and for as much time as possible in the regular classroom. For infants and toddlers, the word inclusion means being included in the community with other youngsters who may be described as typical. Infant/toddler programs may or may not be located in public schools. Settings for their programs may be home-based; they may be with Headstart or any other community program. The emphasis is somewhat different as well - the emphasis is on using the resources of the community to provide services to the child *and* family.

School based health needs have been difficult to provide. Limitations placed on nurses and other health personnel through the Nurse Practice Act were prohibitive. Until last year's legislative session, there was little which could be done to relieve the burden placed on nurses in schools. Some relief was found in the delegatory clause language which was added last year, and now nurses may exercise judgment about the delegation of certain health services.

Finally, Colorado through its Parents Encouraging Parents program has provided intensive training and technical assistance to parents of children with disabilities. This program has been active since 1978 and is as vigorous now as it was when it was first introduced. With this effort which has been expanded to include parents of infants/toddlers, we have avoided many of the litigious circumstances found in other states. *(Presenter abstract)*

Open Discussion

1. Q: How does one ensure respect for cultural diversity in especial education?

   A: For example, The Center serves a population that is 25 percent Hispanic, many of whom are non-English speaking. So there is a primarily Spanish speaking teacher in each classroom. *(Brendza)*

   A: Attraction of minorities into parent groups sponsored by agencies has proven difficult. *(Smokoski)*

ISSUES OF ETHICS, ADVOCACY, FUNDING

MODERATOR: Marie Swigert, RN, MS
Director, Community Nursing Section
Colorado Department of Health

SPEAKER: **Kayo Sunada, MD,**
Medical Consultant
Former Medical Director, Division for Developmental Disabilities

The Consequences of Ethical Decisions

Public Law 94-142, enacted in 1975, mandated education for all handicapped children. As amended in 1990, PL 101-476, the Individuals with Disabilities Education Act, primarily deals with identification and provision of services. Part B specifies that "related services - ... medical services shall be for diagnostic and evaluation purposes as may be required to assist a child with a disability to benefit from special education". Many questions and complex problems arise in implementation (see *AAP Committee on Children with Disabilities*, 1992). Nationally and locally, the American Academy of Pediatrics issued reports and held conferences and educational seminars for pediatricians for several years to inform and encourage physician involvement in implementation.

With the implementation of deinstitutionalization came ongoing gravitation from institutional medical care toward home centered care, education for all, and multi-disciplinary treatment. Historically, institutions or tertiary care facilities were "professionally" directed by health care personnel. Today, although resistance is encountered in the medical community, physicians must rethink exclusive reliance upon physician decision-making.

As the severity of physical, emotional, and cognitive disability increases, ethical issues arise that are compounded by advances in medicine. The practice of good clinical pediatrics is the practice of ethical medicine in which decisions should reflect the best interest of the child.

Medical Interventions

Four areas have been identified by Jonsen, Siegler, & Winslade (1982) as considerations for ethical medical decisions:

1. medical need
2. patient preference
3. quality of life
4. external factors (such as technological and scientific advances that enable more home-centered care)

Medical Need

The need for medical intervention is in terms of diagnosis, evaluation, and therapy. Ethical questions associated with clinical assessment are: (a) How much is enough?, (b) Will it change anything?, and (c) Should we really go through this? Such questions arise from cost containment efforts, concerns for risk of excessive suffering, and doubts regarding the incremental value of extraordinary efforts. Similar issues apply to therapeutic interventions--to treat or not (Weber, 1976) -- whether addressing acute or chronic conditions or therapies to maintain or sustain life (including invasive procedures such as tracheostomy, gastrostomy, and catheterization). Regarding invasive procedures, a central question is the procedure's impact upon the quality of life? For the young child, ethical considerations regarding pain should be given the most serious consideration. However, a child's pain is often unappreciated and untreated, while pain therapy is grossly mishandled.

Patient Preferences

Patient preferences and guardian decision-making raise ethical responsibilities to ensure informed consent. Thus, the patient or guardian must comprehend the diagnosis, the proposed therapy, its expected benefits and possible adverse reactions, and the risks and benefits of alternative therapies or the decision not to treat. Communication of this essential information may be complicated by cultural differences. Language difficulties, inadequate explanations, and failure to account for differing values and customs may result in misunderstandings that contribute to poor outcomes for the child and family.

Quality of life

An essential ethical issue is determination of who is to make vital decisions regarding the quality of life on behalf of the birth to three year old population. Decisions, made in the abstract, that categorize some children as less than human readily undermine the moral imperative to fund care. Equally important are decisions assessing the quality of life with and without therapy, terminating or refusing therapy for a child, and allowing or obstructing "death with dignity".

External factors

Several external factors are also raise ethical decisions. Cost is increasingly a primary issue in health policies, as it is for institutions and families. Ethical considerations must also address other effects on the family, such the toll exacted by assuming responsibility for home-centered care, the voluntary nature of decisions, resulting stress, and the probable melding of medical decisions and family decisions. Finally, the principle of utilitarianism may be in direct conflict with the rationale for medical intervention. It simply may not be pragmatic to do what is best for the child, presenting yet another ethical dilemma.

Ethics and Confidentiality

The two underlying questions regarding confidentiality are, What is confidential? and Who needs to know? With the growth of shared decision-making, communication among caretakers increases, increasing threats to confidentiality. Also, who gives "release" permission? AIDS and Hepatitis B pose interesting examples. Caretakers want to be informed, however, guardians may not want information shared, fearing negative reactions of other parents, etc. Perhaps the best solutions will be in universal policies for disposal, hand washing, etc.

Administrative Responsibility

Administrators should develop a philosophy, then set goals and objectives that are compatible with their overall philosophy. The policies and rules of the facility will follow. Within these parameters, administrators should be aware and have an understanding of local, state and federal regulations, as well as of health policies. Administrators must keep open the lines of communication with regulatory boards. They must work within a set budget and establish priorities. They must be sensitive to the development of ethical issues and possess some knowledge of potential mechanisms for their solution. They should realize that selected staff may function as excellent advocates and should discuss with them the responsibilities and the goals of an advocate, including management of potential conflict between the advocate and employee roles. Administrator must also recognize parents as informed advocates.

Conflicting Approaches and Mandates

Ethical and advocacy issues will also emerge from differences in interpretation of mandates (Part H of PL 99-457, Part B of PL 101-476, and Section 504 of the Rehabilitation Act), and from philosophical differences between disciplines. Among the likely points of dissension are: (a) Responsibility for medical therapy; (b) Liability; (c) Responsibility for training and monitoring performance; and (d) Authority and processes in decisions to exclude students for medical reasons (AAP Committee on Children with Disabilities, 1993).

Summary

Because of regulations and mandates, states are continuing to move toward less restrictive, community alternatives for services for individuals with disabilities. Community based health programs are mandated. The rapid advances in medicine in genetics, metabolic diagnostics, therapy alternatives, and sustaining of life --all will result in the need for increased attention to vital moral questions. We need a philosophy for viewing the children with disabilities. If they are less than human their treatment is accordingly degraded. *(Augmented abstract)*

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SPEAKER: **Marie Swigert, RN, MS**
Director, Community Nursing Section
Colorado Department of Health

Ethics and Advocacy for the School Nurse

With the advent of the implementation of the Individuals with Disabilities Education Act (1975, 1990), states must provide early intervention services to infants and young children with complex health needs in regular school, preschool, and child care center settings. This includes the mandate to provide health services, including invasive procedures. This mandate, plus the requirements of state nurse practice acts requiring delegation, has raised concerns of advocacy and ethics with school nurses.

"Should these children be in a regular school setting?", "What about the other children in the classroom?", "Should I and can I, as a school nurse, do the required invasive procedure in the school setting?", and, "What do I as the nurse do to advise the school about a resuscitation order?" are some of the questions asked by nurses as children with complex health needs are in schools.

Nurses have available to them a number of tools to assist them with these questions and the dilemmas they pose. Among them are the references and guidelines prepared and developed by nursing organizations and state departments of health and education. State boards of nursing with regulations concerning delegation are also resources. Collaboration with parents and parent advocacy groups, as well as health care providers (physicians and hospitals), in the development of standards of care and nursing protocols are actions which can be taken to deal with these issues. *(Presenter abstract)*

SPEAKER: **Mary Anne Harvey**
Executive Director, The Legal Center

Recent Decisions Relevant to Special Needs Children

If one begins from the premise that it is more natural for children to be included than excluded, one gets a lot further in the discussion of how we support a child in the school setting. Concerns being raised about including children with complex medical needs are not unlike many of the concerns raised when P.L. 94-142 was first passed. Recent decisions influencing two relevant issues are presented: Children with AIDS and Do Not Resuscitate Orders.

Children with AIDS

Exclusion from day care on the basis of HIV is a violation of the ADA, unless the participation of such individual poses a direct threat to others that cannot be eliminated by a policy or procedural modification. Further, in accordance with the regulations implementing Title III, public accommodations may not exclude people with disabilities on the basis of limitations in insurance coverage.

(From a response to a letter of inquiry from Senator Joseph Biden to the Department of Justice, Civil Rights Division, July 31, 1992.) A child with AIDS generally will be considered "handicapped" under Section 504 due to the substantial limitation on a major life activity caused by either a physical impairment or the reaction of others to the perceived contagiousness of the disease. Children with AIDS are "qualified" under Section 504 if they meet the age-related requirements. Therefore, a child with AIDS is entitled to FAPE, including placement in a regular educational setting, unless the stage of the child's disease currently presents a risk of contagion to others. If the child is handicapped solely because of AIDS, the full evaluation process is only applicable when the child demonstrates a need for special education or related services. In all other respects, however, the child is entitled to the process and procedures of Section 504, including the requirements of the placement decision and the procedural safeguards.

Finally, districts may not treat children with AIDS differently from nonhandicapped students in matters of confidentiality (*U.S. Department of Education Office of Civil Rights Staff Memorandum, April 5, 1990*). For guidance on confidentiality, refer to Someone at School has AIDS, A Guide to Developing Policies for Students and School Staff Members who are Infected with HIV by Katherine Fraser, published by the National Association of State Boards of Education, 1989.

Do Not Resuscitate Orders

OCR investigated a complaint against Lewiston, Maine, Public Schools in which the complainant alleged that the district discriminated against a 12-year-old student with a disability by adopting a directive that denied the student the same life-sustaining emergency care that was provided to other students.
OCR held for the district.

At the time of OCR's investigation, the district had a new policy on life-sustaining emergency care in effect which prohibited it from complying with requests from parents or others to withhold this medical treatment from any student. The district's policy did not distinguish between students with and without disabilities, but did allow for development of individually designed medical resuscitation plans by multidisciplinary school-based teams for students whose individual needs required such plans. OCR determined that this policy did not conflict with Section 504 or Title II of the ADA. OCR also upheld the individual medical resuscitation plan designed for the student in question, which described in positive terms the specific steps to be taken by school personnel if the student required life-sustaining medical care while under the district's supervision and was the only individualized plan in effect at the time of OCR's investigation. The plan was designed by a multidisciplinary team of persons knowledgeable about the student including the student's parent, physician, and appropriate school personnel, was based on expert medical and other relevant information about the student, was appropriately documented, required a second medical opinion, and was of limited duration, ensuring that it would be reevaluated periodically. *(Presenter paper)*

SPEAKER: **Mark Yarborough, PhD**
Associate Professor and Acting Director
Program in Ethics and Medical Humanities
UCHSC School of Medicine

Interests and Obligations in Providing for Children with Special Health Care Needs

Providing for the educational and health care needs of young children with special health care needs can pose difficult challenges for and create strong tensions within the communities where the children live. Meeting the challenges and lessening the tensions will require clear sightedness concerning the issues at stake as well as patience in learning how to solve the problems the children's health care needs pose. A spirit of compromise among the involved parties will also be required.

All children deserve access to educational opportunities which will enhance their lives and promote their well-being. Affluent societies ought not allow special health care needs to deprive some children of these opportunities. Yet this places unprecedented requirements on educators if they are to be prepared to provide for these health care needs so that children can enjoy educational opportunities. Educators must be empowered to provide these new services. While doing so, they must continue to provide for the education and welfare of all the children in their schools. These tasks can be performed adequately by making additional resources and

training available. These resources must come from the communities at a time when community members are increasingly reluctant to pay for any additional services and initiatives. **(Presenter abstract)**

Table 1. Interests and Obligations in Providing for Children with Special Health Care Needs

Parties	**Interests**	**Obligations**
Child	health protected, welfare promoted through access to education	
Child's parents	directing their child's growth and development	provide for their child's needs and interests
Classmates	receiving quality education in a safe environment	
Classmates' parents	directing their child's growth and development	provide for their child's needs and interests
Physicians, Nurses, Paraprofessionals	practicing in accordance with professional standards	provide quality care, consult with parents in regard to medical decisions made on behalf of children
Teachers, School Administrators	having an environment conducive to effective teaching	provide effective education, provide for the safety of children while at school
Taxpayer	maximizing freedom	promote the general welfare

Groupings[1]. Three clusters of parties may be aggregated from the above Table. The child, classmates, child's parents, and classmates' parents comprise the first grouping, concerned with protection of health and acquisition of education. For parent, direction of child growth and development is an additional interest, accompanied by the obligation to provide for child. The second grouping, the professionals, consists of a subset of physicians, nurses and paraprofessionals interested in practicing in accordance with professional standards, and charged with provision of quality care and consultation with parents on medical decisions made on behalf of the children. Teachers and school administrators, the second professional subset, are concerned with maintaining an environment conducive to effective teaching, while they are obligated to provide effective education and to provide for the safety of children at school. The final grouping, taxpayers, must balance maintaining freedoms with an obligation to promote the general welfare.

Ethical Dynamics. In the service of the child/classmate/parents cluster, professionals often may be at odds in meeting their obligations and protecting their interests. If professionals are obligated by society, the taxpayer must provide resources. However, many in the taxpayer group dispute promotion of the general welfare as a taxpayer obligation, viewing it as a legally unenforceable role. Ultimately, the ethical problems will require practice and compromise to be resolved.

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[1] Table explanation summarized by Conference Staff.

Open Discussion

1. Q: Please clarify the legal status of disclosure and AIDS.

   A: Decision to disclose beyond required levels, should be left to the discretion of the individual or guardian. *(Harvey)*

   R: However, the educational value of disclosure should not be overlooked, to minimize the perception of the disease as a "big, dark secret". *(Motz)*

2. Q: What about AIDS and endangering behaviors such as biting?

   A: Open lesions are grounds for exclusion. Aggressive behaviors such as biting may be, although there is no evidence of transmission in any child care setting. Decisions must be made on an individual basis weighing the benefits to the child with special needs versus the risks to others. *(Harvey)*

   A: Universal precautions need to be set in place, so that they are not discriminatory to the disabled individual. *(Swigert)*

SYSTEMS CHANGE: How to Influence Policy Making

MODERATOR: **Patricia Motz, EdD, RN**

SPEAKER: **Patricia Rowell, RN, PhD**
Senior Policy Fellow
American Nurses Association

Systems Change: ANA Perspective

As a general principle, systems change when endangered or in disequilibrium. To keep current and alert to the need for systems change, the American Nurses Association relies on volunteers from among its membership of 205,000. In addition, ANA's readiness to effect systems change has been improved by adoption of a new council structure, the organization of which has shifted away from a pathology-oriented medical model to a systems structure based on site of care (e.g., to acute care or nursing systems in administration).

The implementation of IDEA regarding invasive procedures is one example of an issue brought to the Association's attention by the ANA membership. In response to members' concerns regarding the delegation of nursing tasks to unlicensed assistive personnel (paraprofessionals), ANA issued a position paper in 1992. To further explore the ramifications of the issues related to delegation of nursing responsibilities, a task force of the Center for Ethics and Human Rights was appointed. The task force will soon present its recommendations to the membership.

In the arena of systems change, the most successful strategy is coalition building. It is imperative for professionals and other interested parties to work together to define problems and achieve workable solutions. Thus, professional-consumer coalitions are essential to efforts to accomplish systems change. ANA's role in these efforts is to continuously scan the environment for relevant information and to be aware and supportive of the co-players. *(Staff summary)*

SPEAKER: **David Stockford**
President, National Association of State Directors of Special Education
Director, Division of Special Services, Maine Department of Education

Education Reform

All across the country initiatives have begun at local, state and national levels in an effort to reform education. There is no single reform effort, rather a multiplicity of initiatives have been undertaken. Significant stress results from the many changes in the service delivery systems for children and their families. We experience substantial debate as a variety of interest groups attempt to influence change at all levels and, in particular, shape developments through federal legislation.

The National Association of State Directors of Special Education began to define the roles of special education and special educators in these reform efforts through a paper titled, Leading and Managing for Performance: An Examination of Challenges Confronting Special Education. Key to this transition is a focus on moving from a process of educating students to attention to a performance-based system.

We are experiencing, and will experience, changes in strategies to initiate, modify or expand policies which direct the provision of services. It is important to identify the levels of policy making one wishes to influence and recognize the practices that will be impacted. Key is understanding of the variety of polices which often have developed in isolation and which are program-specific. The effort to modify or correct practices, as a result of newly identified or emerging needs, has created numerous barriers to comprehensive planning.

Variables which need to be considered include

- the leadership role of catalyst;
- the commitment to the time and energy necessary;
- the sharing of power and authority;
- patience;
- learning from our experiences;
- public and private participation; and
- knowledge of children and families.

Numerous trial and error efforts can provide guidance. The somewhat experimental nature of restructuring must allow us to examine failures as well as successes. *(Presenter abstract)*

SPEAKER: **John Nackashi, PhD, MD**
Associate Professor, Medical Director
Pediatric Care Coordination Program and Pediatric Home Care
University of Florida and American Academy of Pediatrics
Committee on Children with Disabilities

Guidelines to Enlisting Physician Support for Systems Change

Physicians need to participate in policy making and programmatic evaluation of services for infants, toddlers, and children. For most people, including physicians, change is difficult. A famous and wise pediatrician once said that "the only individual who likes change is a baby in a wet diaper".

There are no guaranteed ways to encourage physicians to join you to influence policy making, but here are some guidelines:

- Develop a vision for children which ensures that CSHCN grow and develop to their maximal potential.
- The vision should be based on underlying principles promoting the best outcome for CSHCN and their families.
- Promote policy making decisions based on principles and what is best for children rather than what is good for you or your organization.
- Approach the physician to work with your team to influence policy making.
- Offer to help and support the physician in his/her involvement.
- Parents of CSHCN who are served by the physician should be members of your team.
- Maintain contact so as to promote a long term child advocacy team relationship.

Systems change requires attitude change and open and fair communication in order to bring together individuals to influence policy making. *(Presenter abstract)*

SPEAKERS: **Kit Hovey**
Parent Advocate
Arapahoe County Early Childhood Network
and
Ashley Hovey
A child with special health care needs

Fostering a Dream for the Child with Special Health Care Needs

I am the parent of a child with special needs who has benefitted immeasurably from inclusion. I have seen directly the benefits that she has received from being mainstreamed with her peers, and I have worked as a parent advocate to help change policies and make systems more family friendly. I remember clearly how I felt at the birth of my daughter Ashley, my third child, who was born with spina bifida. As I began to put the pieces together, I knew that things were going to workout somehow. I just didn't know how. I had a picture lodged in my mind of Ashley sitting in her wheelchair at the edge of a large gym watching all the other children running and playing. In this picture Ashley didn't look unhappy but I felt sad because she wasn't included. I was afraid that life would pass her by; that she was destined to be an observer rather than a participant.

As the months went by my vision began to change. My dream focussed on the fact that Ashley could do and become whatever she wanted. The possibilities were endless she could definitely become independent, be a professional, have lots of friends and relationships, a family, participate in all sorts of activities and sports. She could possibly become an advocate and leader in the disabled community. She had many choices ahead of her. In all of this Ashley hadn't changed; she had always had these possibilities. It was my dream that changed.

A family's dream for their child is a very critical first step in the development cycle of any child but particularly a child with special needs. Without the life goals embodied in the dream it is hard to lean to be independent. If you didn't believe that your child would become an active member of their community and maintain lifelong relationships, then it almost wouldn't matter what he or she learned at school. All that they would need would be a safe environment and good physical care. However, because of our dream for Ashley, it is extremely important that she is fully included, that she be challenged academically with support as necessary, and that we work in partnership with the school in developing her IEP.

Family centered care is a very important building block in enabling a family to begin to realize their dream by starting to take charge of their situation. A child with special needs can then fit in with the tempo of the family, instead of the tempo of the professionals, so that the family can function as a family. Through a grant I have been very involved in this process at Children's Hospital in Denver. Family centered care is the beginning of family empowerment so that the family can be a partner with the medical community in meeting their child's special needs. The family becomes their child's advocate, educating people along the way and ultimately helping to change the system.

For me it was very important that Ashley be able to attend our neighborhood school, but I heard many stories of children with special needs who had been denied entrance to the local school because of perceived problems in providing clean intermittent catheterization (CIC). Since it was considered a medical or health care procedure, many principals refused to accept a child that needed CIC. Luckily our neighborhood school principal did not view it as a problem. However, one family back East was forced to take the issue to the Supreme Court which ruled that all schools needed to perform CIC. In fact, most children learn to self cath in second or third grade.

Another change in the "system" originating from the special needs community is the American Disabilities Act (ADA), a law that has brought much positive change. In my opinion, the "system" is so much more respectful now, fostering self esteem. For example, when bathrooms weren't accessible, we were forced to do catheterization in the car. Today Ashley can wheel herself up a curb cut, use a washroom by herself, enjoy a playground, participate in sports, go to a movie and expect an accessible work place. In short, she has the opportunity to lead a normal life, to build self esteem and to lean to succeed.

Because of our dream, Ashley's accomplishments and her readily apparent self-esteem, I feel that just by being out in the community Ashley is helping to change the system through educating the people that she meets. She is constantly turning heads as she zips down the mall, swims at the local pool or skis black runs at Winter Park or Breckenridge, or wins gold medals in national competition. When we were are buying a swimsuit the other day the salesperson said "Well, it is obvious that you are an athlete!", not a statement that one could have expected just a few years ago. Ashley beamed for the rest of the afternoon.

Advocating is certainly not an easy path but it is certainly rewarding. Ashley is constantly touching someone's life. By getting involved in sports and community activities, she changes people's attitudes, builds her self esteem and establishes relationships; and she spurs me on to continue my work in helping make systems more family friendly. *(Presenter paper, K. Hovey)*

Open Discussion

1. Q: *(To Ashley Hovey)* Please describe your experience as a playground design consultant to address accessibility.

   A: Miss Hovey described her experience reviewing playground design from the perspective of wheelchair accessibility and with attention to surface construction, etc.

2. Q: What is most rewarding part of parent advocacy?

   A: Seeing disabled participating in the life of the community. *(K. Hovey)*

3. Q: How can we help parents who are reluctant to see their child included, parents who are fearful?

   A: Help them develop a vision for their child. Educate them that their child will be valued by others as they value them. Meeting adults with disabilities - as role models - is very helpful. *(K. Hovey)*

   A: Parent anxiety regarding community placement recedes as child has successes in the community. *(Sunada)*

   A: Encourage the child and family in the development of social interactions. *(Nackashi)*

   A: Professionals need a philosophy to help parents have a dream for their child. *(K. Hovey)*

4. Q: How can you encourage a dream for parents of children with extremely severe disabilities?

   A: The goals must be realistic to be respectful. *(K. Hovey)*

August 7, 1994

CHALLENGES FOR THE FUTURE/FUNDING:
Dissemination and Training/Funding Resources:

MODERATOR: Marilyn Krajicek, EdD, RN, FAAN

SPEAKER: **Jim Carlisle**
Marketing Associate
The Children's Hospital
Denver, Colorado

Changes in Provider and Payer Systems Impact on Resources, Access and Delivery of Health Care Services for Special Needs Children

This presentation focuses on the impact on resources associated with the evolving delivery and payer systems, specifically evolving changes in reimbursement and delivery systems.

Funding Resources

Traditional funding for health care services has been via *indemnity coverage* offered by commercial insurance, as well as through *entitlements* including Medicaid, Medicare and SSI/SSDI.

These sources offered relative simplicity of access and procedure compared to today's evolving market. In the current environment of corporatization of health care, access and delivery systems are likely to change, or are already changing.

Issues of access, eligibility and coverage of services inspired the creation of unique funding resources for special needs children, to assist financially pressed parents (e.g., with orthopedic bills) through Handicapped Children's Services (HCP, for coverage of special medical procedures, durable equipment, and limited therapy for selected early development diagnoses), Model 200 (waivers to access Medicaid when there are significant medical needs), Persons Living With Aids (PLWA waivers to access Medicaid regardless of financial resources for a diagnosis of AIDS), and Baby Care (in Colorado, primary care and some specialty services). Such programs designed to serve specific targeted populations have been accomplished at great cost to federal, sate and local government.

Funding Resource Access and Availability

Increased expenditures and escalating health care costs, as well as other factors such as the increase in the number of uninsured Americans, stimulated significant changes in the traditional reimbursement models for health care services. Principal among these changes is the trend towards *capitation* - a dramatically different model of reimbursement. Capitation is the process under which the providers accept a flat monthly fee for each enrolled person regardless of the number of services rendered to each insured individual.

It is predicted that in two years, 93 percent of reimbursement will be based on capitation. The allure of capitation is predictable, fixed revenues, rather than variable revenues based on services rendered. However, capitation reverse the logic of health care delivery.

Under traditional reimbursement models, the incentive was to treat patients -- the provider rendered service and was paid for each instance. Under capitation, the incentive for fiscal efficiency, which equals low utilization. Providers no longer have the incentive to treat. The shifts in incentives may limit access to and delivery of health care services, especially for special needs children.

Table 2. Capitation Reverses the Logic

Performance Measures

	under Fee-For-Service	**under Capitation**
Market Share	# of Admissions # of Procedures # of Visits	# of Covered Lives
Costs	Cost per Procedure Cost per Stay	Cost per Life per Month
Management Focus	High Utilization	Low Utilization

Evolving Payer Systems

In the past, the market distribution of payer systems included a large number of commercial insurers and Medicaid. As recently as 1990, purchasers of service had many choices. While the relative market shares of Medicaid and commercial payers are expected to remain relatively constant, the trend towards market consolidation through collaboration and merging of insurance companies will result in an evolving payer system of fewer commercial payers with proportionately larger shares. In some states, as few as 2 - 3 payer system monopolize payment systems, and urban markets are increasingly moving toward consolidation of payers (a situation already realized in the New Mexico, Atlanta and Minneapolis markets).

These new payer alliances/systems limit the choices among insurance products and decrease the number of key decision makers. The emphasis on affordability decreases emphasis on services and treatment, likely impacting access and service delivery for special needs children.

Emerging Provider Market

Larger payer systems control a greater number of lives (the revenue stream for health care providers), while seeking to align themselves with fiscally efficient providers. Providers in turn explore ways to be more competitive and thus more attractive to payers to gain lucrative payer contracts. Providers also protect themselves from payer control by banding together in integrated delivery networks, resulting in increased negotiating power.
Thus, linkages are forged among primary care providers, hospitals, specialists, clinics and home health care. Through such vertical integration utilization is kept by managing the patient through the continuum of care. The emphasis on low utilization of a vertically integrates provider system produces advantages to providers and payers in terms of cost efficiency and effective care management -- gatekeeping through partnerships.

Successful provider integration efforts produced two popular models: Management Service Organizations (MSOs) and Physician Hospital Organizations (PHOs). The formal allegiances established through physician/hospital integration help to increase market share for providers by increasing negotiating power with payers and decreased operational expenses through the consolidation of services. Once again, the implications for the consumer are decrease choices and a decreased number of key decision makers.

What to Expect in the Future

Payers and providers now look for increased insured bodies and decreased utilization. Health Care reform can be expected to impact access. Developments both in the payer and provider systems increasing emphasize cost and decreased utilization, shifting financial incentives so that they impact delivery and access to services. Therefore, these changes can be expected to increase the challenge to special needs children to have access to necessary services and providers.

The risks posed to the consumer demand accountability and performance measures. Accountability may be defined in terms of access to services and services that meet the needs.

Performance measures should emphasize quality. Quality is not a factor in the business decisions that drive the emerging payer and provider systems.

How to Make a Difference for the Future Health and Welfare of Children:
A Call To Action

Many forces have impacted health care delivery since 1970, such as cost reimbursement during the 70s, DRGs, Managed Care, technological advances, and an aging population in the 80s, while the current decade promises many more potential changes (e.g., health care reform, a single payer system). How much do you know about the changes occurring in your communities? How will these changes affect the access and delivery of needed services for the special needs children of your communities?

These challenges require that you

- become involved with your community providers and the key decision makers both government and private corporations;
- hold them accountable for assuring that services for special needs children continue to be accessible and affordable and that minimum quality standards exist;
- explore creative alternatives to traditional provider services that help to share the burden of health care expense: collaboration among community agencies; cultivate grass roots resources and involvement;
- maintain an active level of involvement with the key decision makers of your communities; and
- stay informed. *(Presenter outline merged with staff summary)*

SPEAKER: **Jo Shackelford**
Technical Assistance Coordinator
National Early Childhood Technical Assistance System
Frank Porter Graham Child Development Center
University of North Carolina
Chapel Hill, NC

Training/Funding/Resources: What will you need?

With the passage of key federal legislation supporting provision of services to very young children with disabilities in least restrictive environments or most natural environments, increasing numbers of children with complex medical conditions are being served in such settings as day care centers, private and public preschools, Head Start Programs and other community programs where children without disabilities participate.

Recent technological advances have made specialized equipment and administration of invasive procedures and medications to young children with chronic illnesses and disabilities common in these community settings. The challenge is to provide the training and support to day care providers, preschool teachers and other personnel to safely perform these procedures. Nurses may also need updates in clinical skills in order to perform new techniques and to teach or supervise other personnel. Training and support not only promotes health and safety but also a higher comfort levels of staff which will help ensure that the children with disabilities are welcome in community settings.

What resources are available to assist programs or agencies in providing these specialized health care services to young children? It is the purpose of this presentation to help participants identify some possible resources at the local, state, and national levels. There are many resources and opportunities for collaborative training and technical assistance available. However, it is clear that a creative, interdisciplinary, interagency strategic approach to combining funds and personnel resources is required.

The handout packet accompanying the presentation[2] contains more detailed descriptions of resources and lists of contact information. Major sources of funding, training and technical assistance, and information materials are identified. Some examples of successful collaborative strategies used by selected states, community agencies, or organizations are described.

Local Resources

At the local level, resources correspond to the uniqueness of the community. Some resources that would likely be common to most communities are

- families;
- primary health care providers;
- home health agencies;
- public health departments; and
- local philanthropic funds, United Way, Civic Groups, and Churches.

State Resources

Part H Lead Agency and Section 619/Preschool Program of the State Education Agency, and the State Interagency Coordinating Council

An important piece of P.L. 99-457, now the Individuals with Disabilities Act (IDEA), is that services for young children with disabilities must be provided in the most natural environment, settings where children of the same age and without disabilities would participate, and that supportive services needed to enable the child with a disability to benefit from early intervention services in that environment must be provided. This includes health services.

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[2] Refer to annotated bibliography for availability of packet contents.

Health services under IDEA are defined as "services necessary to enable a child to benefit from other early intervention services during the time that the child is receiving the other early intervention services." This includes such services as clean intermittent catheterization, tracheostomy care, tube feeding, the changing of dressings or colostomy collection bags, and other health services.

IFSP and Service Coordination

IDEA Part H requires that every eligible child and family have an *Individualized Family Service Plan*, developed by the family and interdisciplinary team, which outlines needed services and the location in which the services are to be provided. A family *service coordinator* is assigned whose responsibilities are to assist families to access needed services identified on the IFSP and coordinate efforts of all providers involved. If health services are needed to ensure successful inclusion of a child in an integrated community setting, it should be identified as a need on the IFSP and the service coordinator could assist in finding needed training and support for the service providers in that setting.

Every state implementing IDEA is required to ensure that early intervention personnel are appropriately and adequately prepared and trained. States must have interdisciplinary personnel standards and a *Comprehensive System for Personnel Development* including preservice education and inservice training and/or technical assistance. The state task force that plans and implements this component of IDEA is a resource for developing training for personnel regarding health services or for identifying opportunities for training collaboration among a variety of state/local organizations. Part H Coordinators and 619/Preschool Coordinators in the state should be the first contact to explore this resource.

For example: The state of Utah is looking closely at the integration of health services in early intervention and would be good resources to talk to. Contacts for further information are Joyce Lacy, Part H Coordinator at the Department of Health (801/584-8226), and Athlene Godfrey, University of Utah, School of Nursing (801/581-8274).

(A list state early childhood program personnel for every state is included in your packet.)

State Maternal and Child Health Title V Agency

The Title V agency, Children with Special Health Care Needs, is an excellent resource for collaborative training plans. Title V agencies are supported by the federal Maternal and Child Health Block Grant. There is one in every state and it is usually, but not always, in the state Department of Health, Maternal and Child Health.

For Example: In Maryland the *Specialized Health Needs Interagency Collaboration (SHNIC)* is a statewide technical assistance project to assist in management of specialized health needs within early intervention, preschool and school settings. The project is a collaborative effort of the Maryland State Departments of Education (Division of Special Education) and Department of Health and Mental Hygiene (Title V) and the Kennedy Institute for Handicapped Children (University Affiliated Program). A team of nurse specialists offers training and technical assistance to community provides and schools, maintains a telephone hotline for urgent questions, and provides on-site consultation. (Infants and Young Children, 1988, 1(2), 74-84.)

Child Care Lead Agency for the Child Care Block Grant

The Child Care and Development Block Grant of 1990 provided funds to states to improve the availability and quality of child care. One requirement of the legislation was that states use a certain percentage of funds (20%) for child care quality improvement activities including providing training and technical assistance to child care providers in areas such as health and safety. The state Child Care Lead Agency should be contacted as a possible resource. (A list of state Child Care and Development Block Grant Lead Agencies is included in packet.)

Universities, Professional Schools, University Affiliated Programs (UAP)

For Example: *University of Colorado School of Nursing* produced a series of videos which demonstrate specialized health procedures for young children such as CPR, emergency procedures for choking, gastrostomy and tracheostomy care, oxygen, infection control, positioning, and feeding infants and young children with special needs. (Available from: Learner Managed Designs, 2201 K West 25th St., Lawrence, KS 66047)

Every state has *University Affiliated Programs (UAP)* which are interdisciplinary training programs that address needs of children and adults with disabilities. Some of these programs provide training to personnel in other service systems to increase their capacity to serve children with disabilities. The American Association of University Affiliated Programs (AAUAP) can provide information on state UAPs and state developmental disabilities services. (Contact: AAUAP, 8630 Fenton Street, Suite 410, Silver Spring, MD 20910, 301/588-8252)

Professional Organizations

State chapters of the *American Academy of Pediatrics (AAP)* are actively involved in early intervention in all states and collaboratively developing special projects that address children's specialized health care needs. (Contact: AAP, 141 Northwest Point Blvd., P.O. Box 927, Elk Grove Village, IL 60007, 708/228-5005)

For Example: The Pennsylvania Chapter of the AAP has operated *Project ECELS*, Early Childhood Education Linkage System, under the leadership of Dr. Susan Aronson. ECELS provides health professional consultation, training, and technical assistance to improve early childhood education programs in the state. The project works closely with the Governor's Office, the State Department of Health, Department of Public Welfare, Department of Education, early childhood educators and health professionals. ECELS serves an estimated 12,000 programs with more than 300,000 children, including child care, Head Start, family child care homes, group homes and nursery schools. Services from ECELS include: (1) linkages between health professionals and child care programs; (2) telephone advice about health issues for early childhood professionals; (3) a free lending library of audiovisual materials; (4) a quarterly newsletter, *Health Link* distribute to all licensed early childhood programs and ECELS health consultants; and (5) arrangements for health and safety training for caregivers, licensing staff, and health consultants for early childhood programs. One of their publications, *Model Child Care Health Policies*, is included in the display packet. A brochure describing the model is in your packet. (Contact: Dr. Susan Aronson, Director, ECELS, PA Chapter, AAP, 610 Old Lancaster Rd., Bryn Mawr, PA 19010-3809, 215/520-9123)

North Carolina is planning to replicate the ECELS model. North Carolina is using a multi-agency approach involving Maternal and Child Health (Title V) that will house and fund a staff of two full time persons for ECELS, NC AAP Chapter, Part H, Developmental Disabilities, Division of Child Development, Child Care, and Smart Start (Governor's early childhood initiative).

State Developmental Disabilities Councils

For Example: In Albion, NY a program has pooled resources to create an integrated day care and preschool program that serves children, including severely involved children, called *Part of the Neighborhood*. This program was described in a recent edition of the *Early Childhood Report*. The planning team included training for staff on a variety of topics, including sign language, play, sensory integration, positioning, handling, seizures, medications, autism, behavior management and hearing impairments. Funding came from a three year grant from the state developmental disabilities council. (Early Childhood Report, February, 1994)

Federal Resources

U.S. Department of Education Office of Special Education Programs (OSEP)

Early Education Programs for Children with Disabilities (EEPCD)

These federally funded model projects address issues of young children with disabilities ages birth to 8 years. They include model outreach, demonstration, inservice and research projects, and provide a variety of resources for service providers including training, training materials and consultation. Descriptions of projects that address health issues or work with children with specialized health needs are included in your packet. One is particularly relevant to this conference topic:

M-FIRST (Medically Fragile Inservice for Related Services Teams) outreach project is a collaborative model project located at the Oregon Health Sciences University in Portland, OR and at the Health Sciences Center of the University of Washington in Seattle, WA. This project has developed a model inservice training program for related services personnel serving infants and young children, birth to age 8 years, who are medically fragile or dependent upon medical technology. Training emphasizes management of medical conditions in center-based or school settings, planning and arranging transitions between service settings, working with families, interdisciplinary process, safety measures, legal issues, a functional approach to educational services, clinical issues, and handling grief and loss. The project is replicating the model in several training sites and has available training manuals and annotated bibliographies of print and video information.

(Contact: Jan Valluzzi, M-FIRST, University of Washington, 206/543-7403 or Pat Haley, M-FIRST, Oregon Health Sciences University, 503/494-2754)

Technical Assistance

The Office of Special Education Programs supports a number of technical assistance and dissemination projects (list included in packet).

*National Early Childhood Technical Assistance System (NEC*TAS)*. NEC*TAS provides technical assistance to state agencies that are implementing Part H and Section 619 of IDEA, including State ICCs, and also to the EEPCD Projects. Information and publications are also available to others who call. NEC*TAS is a collaborative system and each component of the system is an excellent resource in itself for information and consultation. These include the *Frank Porter Graham Child Development Center* at the University of North Carolina, where the coordinating office of NEC*TAS is located; Department of Special Education at the University of Hawaii at Manoa which serves the Pacific Basin; the *Federation for Children with Special Needs* in Boston which is the national parent training center; *Georgetown University Child Development Center, Zero to Three/National Center for Clinical Infant Programs (NCCIP)*, and the *National Association of State Directors Of Special Education (NASDSE)*, all in Washington, DC. (Information about NEC*TAS and its products is included in the packet.)

Telecommunication Networks

NEC*TAS also manages the telecommunication network of *SpecialNet/Early Childhood Bulletin Board* that provides updates and information on the issues of early childhood. Other relevant tele-communications networks include *MCH-Net*, the *Maternal and Child Health Network Project* focusing on mothers and children with special needs, and *SCAN, Shared Communication and Assistance Network*, that focuses on information and resources related to services for persons with disabilities. SCAN is operated by the American Association of University Affiliated Programs (AAUAP). (Contact information for these networks is included in your packet.)

Regional Resource Centers and Federal Resource Center (RRCs). The six RRCs are specialized information and technical assistance centers whose primary clients are state education agencies. The RRCs address issues of early childhood for preschool children ages 3-5, and school aged-children. They have developed information related to provision of special health care needs in preschool and school programs. The Federal RRC is currently housed with another valuable information and technical assistance resource, the *National Information Center for Children and Youth with Disabilities (NICHCY)*. NICHCY maintains national databases that contain information on emerging needs, research and practice for families, advocates, professionals, students and others. (Contact: NICHCY, P.O. Box 1492, Washington, DC 20013, 800/695-0285, 202/884-8200)

Maternal and Child Health Bureau

SPRANS Grants. The Maternal and Child Health Bureau has funded many innovative, family-centered and interdisciplinary training activities through the grants program known as SPRANS, Special Projects of Regional and National Significance. Some recent grants relevant to health services and early intervention are:

Leadership Development for Nurses in Early Intervention Project, University of Kentucky Lexington, KY (606433-5406 or 6687)

Mainstreaming children with Special Health Needs in Child Care Settings, San Diego State University, San Diego, CA (619/594-4668)

Enhanced Health Care for Children with Special Health Care Needs in Schools, University of Iowa, Iowa City, IA (319/359-1118)

For information about SPRANS grants contact Pathfinder Resources, Inc., Midtown Commons, Suite 105, 2324 University Avenue West, St. Paul, MN 55114, 612/647-6905.

Administration for Children, Youth and Families

Head Start Bureau. Head Start maintains Training and Technical Assistance Support Centers (TASCs) to support their grantees. Head Start is a community placement option for young children with disabilities under IDEA.

Head Start also funds *Resource Access Projects (RAPs)* that, among other activities, provide training, materials and other support services to Head Start programs to assist in fully including children with disabilities, mild and more severe. Two of the RAPs serve the Migrant Head Start grantees and the American Indian grantees. (List of RAPs included)

Americans with Disabilities Act Technical Assistance Grant Program (ADA)

The Americans with Disabilities Act Technical Assistance Grant Program provides training, technical assistance, and training materials for day care centers to better serve young children with disabilities. Print materials and videotapes are available describing access, needs and abilities of children with a variety of conditions and special needs, developmental and behavioral issues, and compliance issues. (Contact information is included in the packet.)

National Resource Organizations

Association for the Care of Children's Health (ACCH)

ACCH is an organization for parents and professionals who work with children with special medical needs. ACCH has a catalog of numerous publications and videos on a range of topics related to health care of children and their families. (Contact: ACCH, 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814, 301/654-6549)

Council for Exceptional Children, Division of Early Childhood (CEC/DEC)

This organization addresses issues of early childhood education and has produced information to assist health and education professionals on the management of children with special health needs. One collaborative effort with the National Association of School Nurses and the National Education Association produced *Guidelines for Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Education Setting*. (Contact: The Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091, 703/620-3660)

National Center for Education in Maternal and Child Health/National Maternal and Child Health Clearinghouse (NCEMCH/NMMCHC)

NCEMCH/NMMCHC are information and resource centers on topics specifically relating to maternal and child health. (Contact: NCEMCH, 38th and R Streets, NW, Washington, DC 20057, 202/625-8400)

Private Foundations

Some selected private foundations who fund early childhood or children's health projects are described in the handout packet. These include:

The Robert Wood Johnson. This foundation is one of the largest health care philanthropies in the country. Program goals include assuring health care for all and serving people with chronic health conditions.

United Way of America. Through its "Mobilization of America's Children" program, United Way of America is addressing needs of early childhood development.

W. K. Kellogg Foundation. Efforts of this foundation focus on youth and include support of comprehensive, collaborative, community-based health services.

Danforth Foundation. One focus area is "A Good Beginning for Every Child", supporting parental involvement in child development, staff development for pre-primary and primary school personnel, and transition to school. One project in Chicago involves citizens and professionals in the delivery of early childhood care and education services. Another project in Washington, DC promotes comprehensive services and support for young children with developmental problems and their families.

AT&T Foundation. Project EQUIP (Early Education Quality Improvement Project) works with local communities to assess child care and early education, and to develop and implement plans for improvement. *(Presenter paper)*

SPEAKER: **Julie Beckett**
Co-Director, Family Voices Child Health Specialty Clinic
Iowa City, Iowa

As the parent of a child who has lived on a ventilator for 16 years, and a strong supporter of early intervention services, I'm pleased to join you in the discussion about your state's implementation of IDEA, especially for medically complex children.

Families have a unique perspective often influenced by their own perceptions, the experiences that they have encountered and the attitudes of professionals and the public in general about their children. For a long period of time, families' perspectives were not included in defining policy or implementing training procedures and yet they were the ones who were the most expert in knowing who their children really were -- they didn't see them as a diagnosis or a label. Families were often "labeled" themselves as uncooperative or unrealistic when they did not agree with how their children were being handled either medically or educationally.

With medically complex children further confusion and fear arose because it became difficult to separate medically necessary and appropriate procedures from their educationally significant needs. With the passage of IDEA, we recognized that young children with medical complexity in particular could benefit from educational interventions. The "new kids on the block" as they were often referred to, proved that their medical conditions improved with the challenge of competing with children their own age. What seemed impossible feats before were overcome through the support and encouragement of peers. Integrated day care centers proved to be very successful in meeting the challenges of both children with and those without special health care problems.

Those successes however were often challenged because of concerns with safety and liability. Regulations often brought higher costs, higher costs in turn restricted the number to be served and services became less and less accessible to very complex children. These concerns although sometimes justified established barriers between medical personnel, educational personnel, and families. The simplicity of serving these children as children first and children with complex needs second often times was severed and the illness or condition determined where the child would be located and who would be the primary educator. While the need for protecting these children overshadowed their need for a "normal childhood existence" the overriding health care costs complicated an already difficult issue. Although money was not to enter the discussion under P.L. 94-142, the same philosophy was not always applied to IDEA.

Medically complex children had one other complication, limited "insurance or state Medicaid" funds. How are we to pay for all that is necessary? Controlling health care costs is of course the most important step but what else can or must we do to assure that all children have equal access to a good educational system?

1. First, coordination and cooperation between health, education and social service systems must exist. Real system change must occur.

2. Second, the use of paraprofessionals guided by trained medical and health professionals must become an important part of both education and health systems.

3. Third, the support for ancillary services in non-traditional settings influenced by family-centered, community-based principles must be available.

4. In addition, the establishment of some school-based clinics, support for inter-disciplinary sharing particularly outside the classroom/hospital setting, recognition of others' skills and expertise and the ability to meet these new challenges is needed.

5. Finally, but most importantly, changes in attitude, the sharing of responsibility and acknowledgment that these children have a right to the best education possible so they too can grow into understanding and accepting adults to all individuals - recognizing their personhood first and their challenges second.

We can, as a nation, come together to serve children better. I share my pride in all the accomplishments Katie has achieved with her doctors, nurses, therapists, educators, relatives, and friends. No one of us could have known what a child living on a ventilator would achieve in 1978. The odds of survival in and of itself were poor at best. So to know she spent those first three years of her life in a hospital pediatrics intensive care unit and still started to school on time, overcoming various bouts of difficult illnesses, always staying on top of her school work, starting to high school with the same children she went to kindergarten with, going off to Boston this summer to intern at Exceptional Parent Magazine - all of these wonderful things were accomplished because our community worked together as a whole to make sure she was supported without impediments.

As we look to the future, let's hope we can do the same for every child. How different our world would be if children were at the top of our agenda every day in every way! *(Presenter paper)*

Open Discussion

1. Q: Where do specialists fit in corporatization of health care? Especially considering that the specialist may be the primary care provider for person with special needs.

   A: Financial incentives discourage use of specialists. Financial disincentives are in place for the encouragement of the use of specialists. There is also legislation pending that would affect medical schools for turning out specialists over primary care physicians. Primary care physicians will be the gatekeepers and specialists will be weeded out. *(Carlisle)*

   A: Current national health care reform bills under consideration guarantee access to specialists for children with special needs. However, parents of these children will probably need to opt for the middle and high cost coverage plans to address their children's needs. Parents also need to be active to ensure the care is available to their kids. *(Beckett)*

R: The benefit of more reliance on primary care physicians for care of children with special needs will be to require pediatricians to enhance their skills for meeting these needs. We must utilize health care resources more carefully. The goal and outcome of treatment should receive more emphasis. However, significant family co-payments would be a serious drawback. *(Nackashi)*

A: There is more need to collaborate today. More hospital and physician group collaboration for a close partnership to yield access to services for children with special needs. *(Carlisle)*

R: We need to facilitate parents' needs, to aid them in their acquisition of services, to aid the family. The question is how do we best do this? How do we prevent the family from being overwhelmed by the system? *(Swigert)*

A: One answer is more parents helping other parents, sharing their knowledge and support. Professionals can help, but from a parent perspective, parent knowledge can be more useful. We should also educate consumers to select the appropriate plan. Parents and professionals need to be allied for education and training in how to work within the health care system. *(Beckett)*

R: (On the issue of physicians as gatekeepers to decrease utilization) A provider who refers to specialists is penalized for that referral. An adversarial potential is being set up. The doctor and the family need to be on the same side. *(Comment from the floor)*

A: The physician will see disincentive where the parent will see necessity for a specialized service. It will be the physician and the patient against the payers. What we really need is accurate cost information. What does it really cost to provide a given service? *(Beckett)*

CREATING ACTION PLANS: Discussions and Problem Solving

(Groups moderated by Participants and Project Staff)

Participants formed small groups with common interests and problems (such as medical and legal issues, safe and legal delegation) to better define issues, goals and strategies. At the close of the groups, participants completed individual Action Plans. The Plan defined a problem area, related goal(s) and the strategies that the participant could employ to achieve the goal.

SUMMARY REMARKS

SPEAKER: **Marilyn Krajicek, EdD, RN, FAAN**
Project Director, Policy and Practice to Implement IDEA
Associate Professor, University of Colorado School of Nursing

The goals of the conference were: (1) to encourage participants to stay current with the requirements of IDEA, their State Nurse Practice Acts, and related federal and state legislation; and (2) in the Action Plan groups, to define individual initiatives to pursue at home.

A six-month follow-up is planned to assess the impact of the conference and actions on the individual plans. Sampled conference participants will be contacted on their progress with the Action Plans defined at the conference and their progress in impacting inclusion related to invasive procedures.

Proceedings of the conference will be disseminated, probably by computer networks and availability of diskettes. Future conference offerings will also be announced.

APPENDIX A

LIST OF SPEAKERS

LIST OF SPEAKERS

Julie Beckett
Family Voices Co-Director
Child Health Specialty Clinic
Iowa City, Iowa

Kathleen Brendza
Director
The Center
Leadville, Colorado

Jim Carlisle
Marketing Associate
The Children's Hospital
Denver, Colorado

Rethea Fordyce
President
Denver Federation of Paraprofessionals
Denver, Colorado

Mary Anne Harvey
Executive Director of Legal Services
The Legal Center
Denver, Colorado

Victoria Hertel, R.N., M.S.
Colorado School Health Nursing Colorado
Depts. of Health and Education
Denver, Colorado

Mary Hicks
Parent Advocate
Denver, Colorado

Kit Hovey
Parent Advocate
Board Member, Arapahoe County Early
Childhood Network
Englewood, Colorado

Ashley Hovey
Englewood, Colorado

Marilyn Krajicek, EdD, RN, FAAN
Project Director, Policy and Practice
UCHSC School of Nursing
Denver, Colorado

Marjorie J. Long, JD
Legal Consultant, Attorney at Law
Denver, Colorado

Clair Martin, PhD, RN, FAAN
Dean and Professor
UCHSC School of Nursing
Denver, Colorado

Brian McNulty, Ph.D.
Assistant to the Commissioner
Colorado Department of Education
Denver, Colorado

Patricia Motz, EdD, RNorth Carolina
Consultant, Employee Health Services
Denver Public Schools
Denver, Colorado

John Nackashi, PhD
American Academy of Pediatrics
Committee on Children with Disabilities
Home Care
Pediatric Faculty, University of Florida
Gainesville, Florida

Wendy Nehring, RN, PhD
Past President, Nursing
American Assn. on Mental Retardation
Chicago, Illinois

Sally Phillips, RN, PhD
Past Chair, Colorado State Board of
Nursing
Associate Dean, UCHSC School of
Nursing
Denver, Colorado

Betty Presler, RN, PhD
Faculty, Kentucky College of Nursing
Practice, Early Intervention
Lexington, Kentucky

Patricia Rowell, RN, PhD
Senior Policy Fellow
American Nurses' Association
Washington, DC

The Honorable Patricia Schroeder
Congressional First District
Denver, Colorado

Jo Shackelford, RN, MPH, MA
Technical Assistance Coordinator
National Early Childhood Technical
Assistance System
Chapel Hill, North Carolina

Fred Smokoski, EdD
Director, Special Education Services Unit
Colorado Department of Education
Denver, Colorado

David Stockford
President, National Association of
State Directors of Special Education
Augusta, Maine

Kayo Sunada, MD
Former Director (Ret.)
Colorado Division of Developmental
Disabilities
Golden, Colorado

Marie Swigert, RN, MS
Director, Community Health Nursing
Colorado Department of Health
Denver, Colorado

Mark Yarborough, PhD
Associate Professor & Acting Director
Program in Ethics and
Medical Humanities
UCHSC School of Medicine
Denver, Colorado

APPENDIX B

POLICY AND PRACTICE PROJECT ADVISORY GROUP

POLICY AND PRACTICE PROJECT ADVISORY GROUP

Ms. Joyce Devaney
Maternal Child Health, Nursing
Regional Program Consultant
Dept. of Health & Human Services
1961 Stout Street
Denver, Colorado 80294
PHONE: (303) 844-5955
FAX: (303) 844-6117

Ms. Jan Fleming
American Nurses' Association
Children with Special Needs
Parent-Child Services
Department of Health
Post Office Box 47880
Olympia, WA 98504-7880
PHONE: (206) 586-6721

Dr. Edward Goldson
Interagency Coord. Council
Developmental Pediatrics, AAP
The Children's Hospital
Child Development Center, B-140
1056 East 19th Avenue
Denver, CO 80218
PAGER: (303) 890-8292

Ms. Victoria Hertel
Natl. Assn. School Nurse Consultants
CO School Health Nursing Consultant
Colorado Department of Health
4300 Cherry Creek Drive South
Denver, Colorado 80222-1530
PHONE: (303) 692-2357

Ms. Judith Igoe
Office of School Health
UCHSC School of Nursing, C287
PHONE: (303) 270-7435

Marjorie J. Long, Esq.
Legal Consultant, Attorney at Law
1441 Eighteenth Street, Suite 300
Denver, Colorado 80202-1296
PHONE: (303) 296-9412
FAX: (303) 293-8705

Ms. Doris Luckenbill
Natl. Assn. of School Nurses
Route #1
Box 1902
Fleetwood, PA 19522
PHONE: (215) 987-8519

Dr. Patricia Motz
Denver Public Schools
3375 South Clinton Court
Denver, Colorado 80231
PHONE: (303) 755-1354

Ms. Doris Nay
Associate Executive Director
National Council of State Bds. of Nsg.
676 North St. Clair Street
Chicago, IL 60611-2921
PHONE: (312) 787-6555

Dr. Wendy Nehring
American Assn. on Mental Retardation
Assistant Professor
Dept. Maternal Child Nursing (M/C 802)
College of Nursing
University of Illinois at Chicago
Box 6988
Chicago, Illinois 60680-6998
PHONE: (312) 996-7937
FAX: (312) 997-8871

Dr. Sally Phillips
Colorado State Board of Nursing
UCHSC School of Nursing
Campus Box C288
PHONE: (303) 270-8586

Julia Plotnik
Chief Nurse Officer
US Dept. of Health and Human Services
5600 Fishers Lane, Room 14A-40
Rockville, MD 20857
PHONE: (301) 443-0577
FAX: (301) 443-1719

Dr. Betty Presler **(Consensus Conf. Com. Natl. Stndrds. of Nsg. Px. Early Interv.)**
1753 Blue Licks Road
Lexington, Kentucky 40504
PHONE: (606) 266-2101

Dr. Pat Rowell
Senior Policy Fellow
American Nurses' Association
600 Maryland Avenue, S. W.
Washington, DC 20024
PHONE: (202) 554-4444

Dr. Ann Smith
Nursing Consultant
UCHSC School of Nursing
Campus Box C288
PHONE: (303) 270-8693

Ms. Jo Shackelford
Technical Assistance Coordinator
National Early Childhood Technical Assistance System (NEC*TAS)
Frank Porter Graham Child Dev. Ctr.
University of North Carolina
Chapel Hill, NC 27516
PHONE: (919) 968-9574

Mr. David Stockford
President, National Association of Directors of Special Education
Dept. of Ed., Div. of Special Services
State House Station #23
Augusta, Maine 04333
PHONE: (207) 287-5950
FAX: (207) 287-5900

Ms. Marie Swigert
Colorado Department of Health
Community Nursing Section
4300 Cherry Creek Drive South
Denver, Colorado 80222-1530
PHONE: (303) 692-2361

APPENDIX C

NATIONAL COUNCIL OF STATE BOARDS OF NURSING

NATIONAL COUNCIL OF STATE BOARDS OF NURSING, INC.
BOARDS OF NURSING

Alabama Board of Nursing
P. O. Box 303900
Montgomery, AL 36130-3900
Phone: (205) 242-4060
Fax: (205) 242-4360

Alaska Board of Nursing
P. O. Box 110806
Juneau, AK 99811-0806
Phone: (907) 465-2544
Fax: (907) 465-2974

Alaska Board of Nursing
Department of Commerce and
Economic Development
Div. of Occupational Licensing
3601 C Street, Suite 722
Anchorage, AK 99503
Phone: (907) 561-2878
Fax: (907) 562-5781

American Samoa Health Service
Regulatory Board
LBJ Tropical Medical Center
Pago Pago, American Samoa 96799
Phone: 011 (684) 633-1222, Ext. 206
Fax: 011 (684) 633-1869

Arizona State Board of Nursing
1651 E. Morten Ave., Suite 150
Phoenix, AZ 85020
Phone: (602) 255-5092
Fax: (602) 255-5130

Arkansas State Board of Nursing
University Tower Building, Suite 800
1123 South University
Little Rock, AR 72204
Phone: (501) 686-2700
Fax: (501) 686-2714

California Board of Registered Nursing
P. O. Box 944210
Sacramento, CA 94244-2100
Phone: (916) 322-3350
Fax: (916) 327-4402

California Board of Vocational Nurse
and Psychiatric Technician Examiners
2535 Capitol Oaks Drive, Suite 205
Sacramento, CA 95833
Phone: (916) 263-7800
Fax: (916) 263-7859

Colorado Board of Nursing
1560 Broadway, Suite 670
Denver, CO 80202
Phone: (303) 894-2430
Fax: (303) 894-2821

Connecticut Board of Examiners
for Nursing
150 Washington St.
Hartford, CT 06106
Phone: (203) 566-1041
Fax: (203) 566-6606

Delaware Board of Nursing
Margaret O'Neill Building
P. O. Box 1401
Dover, DE 19903
Phone: (302) 739-4522
Fax: (302) 739-2711

District of Columbia Board
of Nursing
614 H. Street N.W.
Washington, DC 20001
Phone: (202) 727-7468
Fax: (202) 727-8030

Florida Board of Nursing
111 Coastline Dr., E., Suite 516
Jacksonville, FL 32202
Phone: (904) 359-6331
Fax: (904) 359-6323

Georgia State Board of
Licensed Practical Nurses
166 Pryor St., S.W.
Atlanta, GA 30303
Phone: (404) 656-3921
Fax: (404) 651-9532

Georgia Board of Nursing
166 Pryor St., S.W.
Atlanta, GA 30303
Phone: (404) 656-3943
Fax: (404) 651-9532

Guam Board of Nurse Examiners
P. O. Box 2816
Agana, Guam 96910
Phone: 011 (671) 734-7295(6)
Fax: 011 (671) 734-2066

Hawaii Board of Nursing
P. O. Box 3469
Honolulu, HI 96801
Phone: (808) 586-2695
Fax: (808) 586-2689

Idaho Board of Nursing
280 N. 8th St., Suite 210
Boise, ID 83720
Phone: (208) 334-3110
Fax: (208) 334-3262

Illinois Department of
Professional Regulation
320 W. Washington St., 3rd Flr.
Springfield, IL 62786
Phone: (217) 785-9465
Fax: (217) 782-7645

Illinois Department of
Professional Regulation
100 W. Randolph, Suite 9-300
Chicago, IL 60601
Phone: (312) 814-2715
Fax: (312) 814-3154

Indiana State Board of Nursing
Health Professions Bureau
402 W. Washington St., Room 041
Indianapolis, IN 46204
Phone: (317) 232-2960
Fax: (317) 233-4236

Iowa Board of Nursing
State Capitol Complex
1223 E. Court Ave.
Des Moines, IA 50319
Phone: (515) 281-3255
Fax: (515) 242-5908

Kansas State Board of Nursing
Landon State Office Building
900 S.W. Jackson, Suite 551-S
Topeka, KS 66612-1230
Phone: (913) 296-4929
Fax: (913) 296-3929

Kentucky Board of Nursing
312 Wittington Pkwy., Suite 300
Louisville, KY 40222-5172
Phone: (502) 329-7000
Fax: (502) 329-7011

Louisiana State Board of Nursing
912 Pere Marquette Bldg.
150 Baronne St.
New Orleans, LA 70112
Phone: (504) 568-5464
Fax: (504) 568-5467

Louisiana State Board of
Practical Nurse Examiners
3421 N. Causeway Blvd., Suite 203
Metairie, LA 70002
Phone: (504) 838-5791
Fax: (504) 838-5279

Maine State Board of Nursing
State House Station #158
Augusta, ME 04333-0158
Phone: (207) 624-5275
Fax: (207) 624-5290

Maryland Board of Nursing
4140 Patterson Ave.
Baltimore, MD 21215-2299
Phone: (410) 764-5124
Fax: (410) 358-3530

Massachusetts Board of
Registration in Nursing
Leverett Saltonstall Bldg.
100 Cambridge St., Room 1519
Boston, MA 02202
Phone: (617) 727-9962
Fax: (617) 727-2197

Bureau of Occupational and
Professional Regulation
Michigan Department of Commerce
Ottawa Towers North
611 W. Ottawa
Lansing, MI 48933
Phone: (517) 373-1600
Fax: (517) 373-2179

Minnesota Board of Nursing
2700 University Ave. W., #108
St. Paul, MN 55114
Phone: (612) 642-0567
Fax: (612) 642-0574

Mississippi Board of Nursing
239 N. Lamar St., Suite 401
Jackson, MS 39201
Phone: (601) 359-6170
Fax: (601) 359-6185

Missouri State Board of Nursing
P. O. Box 656
Jefferson City, MO 65102
Phone: (314) 751-0681
Fax: (314) 751-0075

Montana State Board of Nursing
111 N. Jackson
P. O. Box 200513
Helena, MT 59620-0513
Phone: (406) 444-2071
Fax: (406) 444-7759

Bureau of Examining Boards
Nebraska Department of Health
P. O. Box 95007
Lincoln, NE 68509
Phone: (402) 471-2115
Fax: (402) 471-0383

Nevada State Board of Nursing
P. O. Box 46886
Las Vegas, NV 89114
Phone: (702) 739-1575
Fax: (702) 739-0298

Nevada State Board of Nursing
1755 E. Plumb Lane, Suite 260
Reno, NV 89502
Phone: (702) 786-2778
Fax: (702) 322-6993

New Hampshire Board of Nursing
Health & Welfare Bldg.
6 Hazen Dr.
Concord, NH 03301-6527
Phone: (603) 271-2323
Fax: (603) 271-6605

New Jersey Board of Nursing
P. O. Box 45010
Newark, NJ 07101
Phone: (201) 504-6493
Fax: (201) 648-3481

New Mexico Board of Nursing
State Education Department
Cultural Education Center, Rm. 3023
Albany, NY 12230
Phone: (518) 474-3843/3845
Fax: (518) 473-0578

North Carolina Board of Nursing
P. O. Box 2129
Raleigh, NC 27602
Phone: (919) 782-3211
Fax: (919) 781-9461

North Dakota Board of Nursing
919 South 7th St., Suite 504
Bismarck, ND 58504-5881
Phone: (701) 328-2974
Fax: (701) 328-4614

Commonwealth Board of Nurse Examiners
Northern Mariana Islands
Public Health Center
P. O. Box 1458
Saipan, MP 96950
Phone: 011 (670) 234-8950 thru 8954
Fax: 011 (670) 234-8930

Ohio Board of Nursing
77 S. High St., 17th Floor
Columbus, OH 4326-0316
Phone: (614) 466-3947
Fax: (614) 466-0388

Oklahoma Board of Nursing
2915 N. Classen Blvd., Suite 524
Oklahoma City, OK 73106
Phone: (405) 525-2076
Fax: (405) 521-6089

Oregon State Board of Nursing
Suite 465
800 NE Oregon St., Box 25
Portland, OR 97232
Phone: (503) 731-4745
Fax: (503) 731-4755

Pennsylvania State Board of Nursing
P. O. Box 2649
Harrisburg, PA 17105
Phone: (717) 783-7142
Fax: (717) 772-1892

Commonwealth of Puerto Rico
Board of Nurse Examiners
Call Box 10200
Santurce, PR 00908
Phone: (809) 725-8161 or (809) 725-7904
Fax: (809) 725-7903

Rhode Island Board of Nurse
Registration & Nursing Education
Cannon Health Bldg.
Three Capital Hill, Room 104
Providence, RI 02908-5097
Phone: (401) 277-2827
Fax: (402) 277-1272

South Carolina State Board of Nursing
220 Executive Center Dr., Suite 220
Columbia, SC 29210
Phone: (803) 731-1648
Fax: (803) 731-1647

South Dakota Board of Nursing
3307 S. Lincoln Ave.
Sioux Falls, SD 57105-5224
Phone: (605) 335-4973
Fax: (605) 335-2977

Tennessee State Board of Nursing
283 Plus Park Blvd.
Nashville, TN 37247-1010
Phone: (615) 367-6232
Fax: (615) 267-6397

Texas Board of Nurse Examiners
P. O. Box 140466
Austin, TX 78714
Phone: (512) 835-2071
Fax: (512) 835-1367

Texas Board of Vocational
Nurse Examiners
9101 Burnet Rd., Suite 105
Austin, TX 78758
Phone: (512) 835-2071
Fax: (512) 835-1367

Utah State Board of Nursing
Div. of Occupational & Prof. Licensing
P. O. Box 45805
Salt Lake City, UT 84145-0805
Phone: (801) 530-6628
Fax: (801) 530-6511

Vermont State Board of Nursing
109 State St.
Montpelier, VT 05602-1106
Phone: (802) 828-2396
Fax: (802) 828-2853

Virgin Islands Board of
Nurse Licensure
Veterans Drive Station
P. O. Box 4247
St. Thomas, U.S. Virgin Islands 00803
Phone: (809) 776-7397
Fax: (809) 777-4003

Virginia Board of Nursing
6606 W. Broad St., 4th Floor
Richmond, VA 23230-1717
Phone: (804) 662-9909
Fax: (804) 662-9943

Washington State Nursing Care
Quality Assurance Commission
Department of Health
P. O. Box 47864
Olympia, WA 98504-7864
Phone: (206) 753-2686
Fax: (206) 586-5935

West Virginia Board of Examiners for
Registered Professional Nurses
101 Dee Dr.
Charleston, WV 25311-1620
Phone: (304) 558-3596
Fax: (304) 558-3666

West Virginia State Board of
Examiners for Practical Nurses
101 Dee Dr.
Charleston, WV 25311-1688
Phone: (304) 558-3572
Fax: (304) 558-3666

Wisconsin Department of Regulation
and Licensing
1400 E. Washington Ave.
P. O. Box 8935
Madison, WI 53708-8935
Phone: (608) 266-0257
Fax: (608) 267-0644

Wyoming State Board of Nursing
Barrett Bldg., 2nd Floor
2301 Central Ave.
Cheyenne, WY 82002
Phone: (307) 777-7601
Fax: (307) 777-6005

APPENDIX D

POLICY AND PRACTICE ABBREVIATION LIST

POLICY AND PRACTICE ABBREVIATION LIST

AAMR	American Association of Mental Retardation
ANA	American Nurses Association
CBSN	Colorado State Board of Nursing
CDE	Colorado Department of Education
CDH	Colorado Department of Health
CDHS	Colorado Department of Human Services
CEC/DEC	Council on Exceptional Children
CP	Cerebral Palsy
DD	Developmental Disability
DOE	Department of Education (national)
DPS	Denver Public Schools
ECE	Early Childhood Education
ICC	Interagency Coordinating Council
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
MCH	Maternal Child Health
MR	Mental Retardation
NASDSE	National Association of State Directors of Special Education
NAEYC	National Association for the Education of Young Children
NAPAS	National Association of Protection and Advocacy Services
NASN	National Association of School Nurses
NASSNC	National Association of State School Nurse Consultants
NECTAS	National Early Childhood Technical Assistance Program
Part H	IDEA: Coordination of services for children 0-3 yrs
Part B	IDEA: Coordination of Services for children 3-5 yrs
TCH	The Children's Hospital

APPENDIX E

POLICY AND PRACTICE RESOURCE TABLE

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POLICY AND PRACTICE RESOURCE TABLE

Ordering Information

The following publications are available through:

National Maternal & Child Health Clearinghouse
8201 Greensboro Drive #600
McLean, VA 22101
(703) 821-8955

A Reader's Guide for Parents of Children with Mental, Physical or Emotional Disabilities

MCH Related Federal Programs: Legal Handbooks for Programs Planners (SSI Income for Disabled Children)

Family/Professional Collaboration for Families with Children with Special Health Needs and Their Families

Getting a Head Start on HIV

Developing a Community-based System for Children with Special Health Care Needs and Their Families: An Overview

Project Spoon: Special Program of Oral Nutrition for Children with Special Needs

Legal Issues in Pediatric HIV Practice: A Handbook for Health Care Providers

Children with Special Needs: A Resource Guide

Surgeon General's Report: Children with Special Health Care Needs

Family-centered Health Care for Medically Fragile Children

Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate Other Craniofacial Anomalies

Circles of Care and Understanding: Support for Fathers of Children with Special Needs

A National Goal: Building Service Delivery Systems for Children with Special Health Care Needs and Their Families

The Open Door: Parent Participation in State Policymaking about Children with Special Health Care Needs

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National Health and Safety Performance Standards: Guidelines for Out-of-home Child Care Programs

Families on the Move

The following publications are available through:

Learner Managed Designs PO Box 3067
Lawrence, KS 66046
(913) 842-9088

Home Gastrostomy Care for Infants and Young Children (plus student booklet)

Home Tracheostomy Care for Infants and Young Children (plus student booklet)

Clean Intermittent Catheterization (plus student booklet)

Positioning for Infants and Young Children with Motor Problems (plus student booklet)

Communication with Preverbal Infants and Young Children (plus student booklet)

Feeding Infants and Young Children with Special Needs (plus student booklet)

Home Oxygen for Infants and Young Children

Infection Control in Child Care Settings

Handbook for the Care of Infants and Toddlers with Disabilities and Chronic Conditions

The following publications are available through:

Project School Care
Children's Hospital
300 Longwood Ave
Gardner 610
Boston, NA 02115
(617) 735-6714

Children Assisted by Medical Technology in Educational Settings: Guidelines for Care

Children Assisted by Medical Technology in Educational Settings: Resources for Training

The following publications are available through:

The Legal Center
455 Sherman Street #130
Denver, CO 80203
(800) 332-6356

The Future of Children with Disabilities is in Your Hands: Handbook of Rights to Special Education in Colorado

The Future ... Hands: Supplement to the Handbook of Rights to Special Education in Colorado: A Guide for Parents

First Steps to Discovery

Other materials from various sources:

AAUAP 1994 Resource Guide
AAUAP
8630 Fenton St., #410
Silver Spring, MD 20910
(301) 588-8252

1993 National Nursing Standards of Nursing Practice for Early Intervention Services
Division of Parent-Child Nursing
College of Nursing
Univ. of Kentucky Chandler Medical Center
Lexington, KY 40536-2322

The Medically Fragile Child in the School Setting (item #451)
American Federation of Teachers
555 New Jersey Ave., N.W.
Washington, DC 20001

Administrator's Policy Handbook for Preschool Mainstreaming
Brookline Books P.O. Box 1046
Cambridge, MA 02238-1046

Managing the School Age Child with a Chronic Health Condition
Sunrise River Press
11481 Kost Dam Road
North Branch, MN 55056
(800) 551-4754

Management of Students with Health Impairments in the School Setting
Illinois State Board of Education
100 North First Street
Springfield, IL 62777-0001

Caregiver Education Guide for Children with Developmental Disabilities
Aspen Publishers, Inc.
200 Orchard Ridge Drive, #200
Gaithersburg, MD 20878
(800) 638-8437

RESOURCES AND REFERENCES

Procedure Guidelines for Health Care of Special Needs Students in the School Setting. Colorado Department of Education and Colorado Department of Public Health and Environment; 1988. (This manual is being revised and expected to be available by October 1994.)

Haynie M., Palfrey J., Porter S. *Children Assisted by Medical Technology in Educational Settings: Guidelines for Care.* Project School Care, The Children's Hospital, Boston; 1989. (This manual is updated periodically.)

Standards of School Nursing Practice. American Nurses Association; 1983.

An Evaluation Guide for School Nursing Practice: Designed for Self and Peer Review. National Association of School Nurses; 1985.

Evaluating School Nursing Practice: A Guide for Administrators. American School Health Association; 1987.

NOTE: The three above publications are a series jointly developed by five nursing organizations and available from American School Health Association.

Guidelines for the Delineation of roles and responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting. Developed by The Joint Task Force for the Management in Children with Special Health Needs; 1990. (Order from The Council for Exceptional Children, Reston VA)

Guidelines for a Model School Nursing Service Program. National Association of School Nurses; 1990

Proctor S., Lordi S., Zaiger D. *School Nursing Practice: Roles and Standards.* National Association of School Nurses; 1993

Enhancing Quality - Standards and Indicators of Quality Care for Children with Special Health Care Needs. Washington DC: US Department of Health & Human Services, Bureau of Maternal and Child Health; 1989.

Infectious Disease in the Child Care Setting: Guidelines for Child Care Providers. Colorado Department of Public Health and Environment; 1990.

Guidelines for School Nursing Documentation: Standards, Issues and Models. National Association of School Nurses; 1992.

Chauvin V. *Students with Special Health Care Needs: A Manual for School Nurses.* National Association of School Nurses; 1994.

APPENDIX F

SPEAKER HANDOUT: R. FORDYCE AND P. MOTZ

SAMPLE PACKET

TRAINING PACKET

FOR

SCHOOL NURSES/PARAPROFESSIONALS

Denver Public Schools
Denver, Colorado

For:

MEETING THE CHALLENGE OF INCLUSION FOR YOUNG CHILDREN WITH SPECIAL HEALTH CARE NEEDS - DEVELOPING POLICY AND PRACTICE TO IMPLEMENT IDEA RELATED TO INVASIVE PROCEDURES

August 6 - 7, 1994

Patricia A. Motz, Ed.D., R.N.C.
Consultant, Employee Health Services

Rethea Fordyce, President
Denver Federation of Paraprofessionals

DENVER PUBLIC SCHOOLS
Department of Health Services
Nursing Service

INVASIVE PROCEDURES – HEALTH GUIDELINES

All personnel who work with special needs students in the school setting requiring any special invasive procedures must:

1. Confer with the school registered nurse to review the Health Care Plan (see attachment) for special adaptations.
2. Adhere to the physician's orders.
3. Follow the specific procedure guidelines as designated by the school registered nurse.
4. Refer to and utilize the "Procedure Guidelines for Health Care of Special Needs Students in the School Setting," Colorado Department of Education and Colorado Department of Health (1988).
5. Report any adverse reactions, concerns or questions to the school registered nurse. Do not continue with the procedure if there are any indications of a problem.
6. Consult with the school registered nurse on a regular basis, i.e. weekly or as needed.
7. Record procedure performed noting date, time, & signature of person performing procedure. Note any pertinent observations.

No DPS employee is to perform any
INVASIVE PROCEDURE
without having specialized training and district approval.

1993/94

DENVER PUBLIC SCHOOLS

SCHOOL
HEALTH CARE PLAN

Student ______________________ Birthdate ______

DIAGNOSIS:

PROBLEMS:

ACTION REQUIRED:

PROCEDURE:

PERSONNEL CAPABLE OF ASSISTING:

Principal	Date
Parent	Date
Nurse	Date
Teacher	Date

8/93

DENVER PUBLIC SCHOOLS
Department of Student Services
Nursing Service

HEALTH CARE PLAN
PHYSICIAN INFORMATION

Dear Physician,

Your patient, ______________________________ D.O.B. __________

is attending __________________. The parents are requesting that specific health care procedures be provided while the student is at school. We are requesting your assistance in identifying the health information and services which are needed in the school setting. Any cost incurred for your participation is at the expense of the family. Members of the school team include the parent, principal, school nurse and other school personnel with direct responsibility for the educational care of the student. We look forward to working with you to provide an optimal educational experience in a safe environment for your patient.

______________________________ __________________
School Nurse Telephone

____

Diagnosis(es):

____

Physical condition for which the procedure is to be performed:

____

Medical orders for procedures and medication which are to be given at school:

____

Precautions, possible untoward reactions, and interventions:

____

Time schedule and/or indication for the procedure:

____

The procedure is to be continued as above until (date):

____

Other:

____

______________________________ __________________
Physician's signature Date

______________________________ __________________
Address Phone

DENVER PUBLIC SCHOOLS
Department of Health Services
Nursing Service

GUIDELINES FOR HANDLING OF BODY FLUIDS

Purpose: These guidelines are meant to offer simple and effective precautions in handling body fluids. No distinction is made between body fluids from pupils with known diseases and/or those from pupils with unknown etiologies (causes of disease) or symptoms.

Definition:	Body fluids include saliva, urine, feces, vomit, respiratory secretions (nasal and oral mucus), drainage from scrapes and cuts, and blood (including menstrual discharge).
Risk:	Body fluids from all people should be considered to present a risk of infection with a variety of germs or infectious agents. In general, the risk is low and it depends on a variety of factors including the type of fluid with the type of contact made with it.
Gloves:	Disposable plastic gloves are available from the DPS Warehouse, Stock #37-1300-02. Glove use is recommended to avoid direct skin contact with body fluids. Hands should also be washed with soap and water when gloves are removed. Gloves should be used only once and then discarded in a plastic lined waste basket or plastic bag and disposed of at the end of each day. Gloves should also be worn to rinse or soak clothing items or towels which are soiled with body fluids. Soiled items should be placed in plastic bags and laundered at home or school with soap, water and bleach. (Add one-half cup of chlorine bleach to the wash cycle.)
Handwashing:	Proper handwashing should be under a stream of water for approximately 10 seconds with soap. Soap suspends and removes micro-organisms and soil particles. Running water carries away debris and dirt. Paper towels should be used in preference to cloth and should be disposed of properly. Frequent hand washing by staff and pupils is the best defense in preventing the spread of germs.
Disinfectants:	Bleach - preferred for objects that may be put in the mouth. One-half cup of household bleach in one gallon of water. Ethyl or isopropyl alcohol 70% - available from DPS Warehouse, Stock #13-0050-00. Disinfectant used by the custodian for cleaning the sinks, drinking fountains and floor is strong enough to kill germs.
Custodians:	Inform custodian of nature of body fluids and request proper disinfectant and disposal. Floors are considered a contaminated area. No special handling is needed for daily floor cleaning or when the vacuum is used on rugs. Mats used to cushion hard surfaces must have plastic covers that can be cleaned with chlorine bleach solutions.

CLEAN INTERMITTENT CATHETERIZATION

Have student independently perform the procedure as completely as possible. Will not be delegated if evidence of an infection, pain, bleeding, or inability to insert catheter.

FEMALE STUDENT:

___ Wash hands

___ Put on disposable gloves if assisting

___ Gather equipment

___ Position student on toilet if student safely can maintain a sitting position have student attempt to void

___ If unable to use the toilet she should lie down with her feet flat on the cot and her knees slightly apart, and her head elevated sufficiently so she can see what she is doing

___ Place an absorbent pad under her hips and thighs if needed

___ Hold or position a mirror so she can identify the anatomical landmarks needed

___ Wash perineal area with soap and water on cotton balls or 4x4s, or use towelette

___ Use a downward stroke to prevent contamination from the rectum; discard into toilet or trash after one sweep

___ Take the catheter out of the storage container and hold it about 1/2 inch from the tip. Lubricate tip with water soluble lubricant if needed

___ Have her locate the meatus with her free hand, gently insert the catheter 2 to 3 inches until urine flows

___ Place the open end of the catheter into the collection container or the toilet

___ Leave the catheter in place until urine ceases to flow

___ Remove the catheter slowly, pause if more urine flows

___ Clean the perineal area with soap and water or a towelette to reduce odor; rinse with water and dry thoroughly

___ Have the student wash the catheter between soapy hands; rinse it well, replace it in the storage container

___ Have the student finish washing his hands, remove and discard your gloves if used, wash hands

___ Document the catheterization on the student's health record or treatment log

---

CLEAN INTERMITTENT CATHETERIZATION

Have student independently perform the procedure as completely as possible. Will not be delegated if evidence of an infection, pain, bleeding, or inability to insert catheter.

MALE STUDENT:

___ Wash hands

___ Put on disposable gloves if assisting

___ Gather equipment

___ Position student on toilet if student safely can maintain a sitting position

___ Have student attempt to void

___ If unable to use the toilet he should sit on a chair or cot

___ Place an absorbent pad under his hips and thighs if needed

___ Obese male may also benefit from a mirror

___ If uncircumcised retract the foreskin, wash the tip of the penis with soap and water or a towelette

___ Position the urine collection container with easy reach if he is not on the toilet

___ Take the catheter out of the storage container and lubricate it from the tip along 2 inches of the tube with a water soluble lubricant then hold the catheter about 1/2 inch from the tip

___ With his free hand have him hold his penis erect and gently insert the catheter into the urethra until urine starts to flow; the insert another inch

___ Some resistance may be felt as the catheter passes the sphincters; slightly increase the traction on the penis and use gentle but firm pressure on the catheter to continue

___ Place open end of the catheter into the collection container or the toilet

___ Leave the catheter in place until urine ceases

___ Remove the catheter slowly, pause if more urine flows

___ Clean the perineal area with soap and water or a towelette to reduce odor; rinse with water and dry thoroughly

___ Residual soap is irritating to the perineum

___ Have the student wash the catheter between soapy hands; rinse it well replace it in the storage container

___ Have the student finish washing his hands, remove and discard your gloves i f used, wash your hands

___ Document the catheterization on the student's health record or treatment log.

TRACHEOSTOMY CARE AND SUCTIONING

(Usually no longer than 3 to 5 minutes, most frequently a clean procedure :

SUCTIONING:

____ Check suction equipment to be sure it works.

____ Wash hands.

____ Prepare the supplies for use:
Place a clean catheter, gauze pads, container of sterile saline on a clean surface.

____ Put on disposable gloves. Use sterile gloves if ordered.

____ Keep one gloved hand clean to handle only the catheter.

____ Attach the suction tube to the suction catheter.

____ Turn on the suction machine.
Have the student take some deep breaths.

____ Suck a small amount of saline through the catheter.
This moistens the tip and confirms the equipment is working correctly.

____ Introduce the catheter through the tracheostomy tube opening, leaving the inner cannula in place.
DO NOT USE SUCTION WHILE INSERTING THE CATHETER.
Insert it the length of the cannula plus 1/4 to 1/2 inch more.
Determine the length by previously measuring the cannula of the reserve tracheostomy tube.

____ Apply suction intermittently while withdrawing the catheter.
Use a rotating motion.

____ Do not have the catheter in the cannula longer than 5 seconds at a time.
The catheter occludes the student's airway.

____ Rinse the catheter.

____ Instill sterile saline drops into the trachea to thin secretions if ordered.

____ Repeat suctioning.

____ If you are unable to clear the trachea there may be a mucous plug.
Follow student's health care plan to clear the plug.

____ Rinse the suction catheter thoroughly.

____ Turn off the suction machine.

____ Disconnect the suction catheter.

____ Remove and discard your gloves. Wash your hands.

____ Reattach the student's oxygen and respirator if they were removed. Observe him until he is stable.

____ Document suctioning the tracheostomy tube on the student's health record or treatment log.

CARE OF TRACHEOSTOMY TUBE AND STOMA:

____ Wash your hands.

____ Gather the needed equipment: Several waxed paper cups, cotton tipped applicators, hydrogen peroxide solution, pipe cleaners, disposable gloves, twill tape pre-cut as tracheostomy ties, skin ointments as ordered, sterile dressing if ordered, adhesive tape if needed for dressing, plastic lined waste container, paper towels, suctioning equipment and sup-plies, clean scissors, sterile saline and/or water.

____ Evaluate the student's condition and behavior to determine if the procedure can be done safely without assistance. If he needs continuous oxygen, is agitated or restless, confused or frightened you will need assistance.

____ Set up work area.
Fill one cup with hydrogen peroxide, a second with sterile saline, a third with boiled water. Lay out the number of applicators, pipe cleaners, gauze pads you think you will need. Arrange the other supplies for easy access.

____ Position the student to expose the tracheostomy area.
Elevate his torso slightly to keep cleansing fluids from migrating into the stoma. A small rolled towel placed under his shoulders will extend his neck.

____ Remove the inner cannula from the peroxide and place it on a paper towel. Using two thickness of pipe cleaner, clean the interior of the inner cannula. Then clean the exterior.

____ Place the inner cannula in the cup of saline to soak briefly.

____ Remove the inner cannula from the cup and pour saline or water over and through it until it is clean and rinsed.

____ Shake off excess moister and place the clean inner cannula in a clean dry cup.

____ Care of the Skin. Clean the skin around the stoma and under the tracheostomy tube with applicators or gauze soaked in hydrogen peroxide.

____ Rinse with water or saline on gauze or applicators.

____ Dry the area thoroughly with gauze or applicators.

____ Reapply gauze dressing, if ordered.

____ Suction the outer cannula if needed.

____ Gently replace the inner cannula if it was removed and cleaned. Lock it in place. Stabilize the outer cannula with your other hand.

____ Observe the student's ventilation and reattach the respirator if needed.

____ Discard all used equipment appropriately.

___ Remove and discard your gloves.

___ Reposition the student for comfort.

___ Wash your hands.

___ Document care of the tracheostomy tube and stoma on the student's health record or treatment log.

GASTROSTOMY FEEDINGS-Gravity Method

___ Encourage student to perform as much as possible

___ Have feeding warmed to room temperature

___ Gather equipment and place next to student position student upright or semi reclining with head at 45 angle

___ Wash hands

___ Use gloves if indicated

___ Check for proper placement of gastrostomy tube: if removable insert one for feeding to pre-marked depth of insertion

___ Gently pull back on tube to make sure tube is tight against stomach wall

___ Attach syringe, unclamp the tube

___ Gently draw back on plunger (if you feel resistance or if you aspirate residual feeding or gastric content the tube is probably in place)

___ Note the amount of gastric content or residual feeding on the markings of the syringe

___ Gently push this fluid back into the stomach

___ Reclamp tube

. If gastrostomy tube is not in properly - do not feed
. If residual aspirate is more than the amount specified by the physician push fluid back into the stomach;
delay the feeding, check student in 30 minutes.

TO FEED: Usually plan 20-45 minutes

___ Attach feeding syringe or gravity feeding bag to clamped tube

___ Fill the syringe/bag with tepid feeding solution - if thick instill a small amount of water before the feeding to moisten the tube unclamp the tube

___ Allow the feeding to flow by gravity with syringe about 4-4 3/4" above student's abdomen

___ Do not apply pressure; gravity will start the feeding

___ Refill the syringe before it is empty until you have used prescribed amount of feeding solution (to avoid introducing air into stomach

___ When feeding is completed instill prescribed amount of water usually 10-30 cc to clear nourishment from the tube

GASTROSTOMY FEEDINGS-Gravity Method (Con't)

Clamp tube before water has cleared from it be sure to check Doctor's orders for clamping - in some cases it may be contra-indicated

___ Place the clamp below the "Y" in the tube to avoid breaking the balloon cover the end of the tube with a 2x2 pad and secure with a rubber band

* NOTE
Observe the student's reactions during the feeding. STOP THE FEEDING if any of the following occur:

a) vomiting

b) respiratory distress

c) sudden distention or signs of left upper quadrant or epigastric pain

d) agitation

e) distention and vomiting

___ Maintain the student's position for 30-60 minutes after feeding

___ Observe the stoma and the skin around the gastrostomy

___ Cleanse with soap and water as needed; rinse and dry

___ Reapply a gauze dressing (folded 2x2) around the stoma

___ Secure the tube to the student's abdomen or to the dressing

___ If the student was unable to consume the entire feeding, measure any remaining nourishment

___ Document the gastrostomy feeding on the student's health record or treatment log

10/93

DENVER PUBLIC SCHOOLS
Department of Health Services
Nursing Service

November 1991

HEALTH GUIDELINES

Non-Invasive Procedures: Assistance to students in the educational environment

DO	DON'T
Do remember, the single best way to maintain and promote health and reduce Illnesses is Frequent Hand Washing!	
Do model good health habits, i.e., hand washing, clean clothes, proper disposal of tissues, covering coughs and sneezes.	Don't come to work when ill or communicable, i.e., active and acute symptoms such as runny nose, frequent cough, vomiting, diarrhea, unidentified rash, skin lesions.
Do Wash Hands Frequently- this is the single-most Important way for staff and pupils to stay healthy. -before and after - feeding pupils -oral/gastrostomy - diapering pupils - toileting (and wiping) pupils - wiping noses and drooling secretions - administering medication - tooth brushing - if assistance is needed - changing sanitary protection Between handling students Do wear gloves when coming in contact with body fluids (see attachment, "Universal Body Fluids Precautions"). Do encourage pupils to wash their hands frequently. This is especially important before eating and after using the bathroom for both staff and pupils.	Don't handle more than one child or perform a different procedure without washing hands.
Do maintain good classroom hygiene. Do wipe off tables after use.	Don't use soiled cloths, sponges for cleaning purposes.

DO	DON'T
Do designate separate feeding, diapering and play/work areas.	Don't use the same surface for diapering, feeding and play/work.
Do clean areas with disinfectant after body fluid(s) spill.	Don't wipe contaminated area without a disinfectant.
Do dispose of body fluids, soiled tissues, diapers, sanitary protectors in a plastic lined waste basket.	Don't allow used articles to accumulate on surfaces or floors without being contained in plastic bags.
Do regard the floor/carpets as a dirty area.	Don't regard items picked up from the floor/carpets as clean.
Do return All eating utensils to the school cafeteria immediately after use to be sanitized. Blenders and some personal items such at adaptive spoons can be cleaned in the classroom using chlorine bleach in the dishwashing pan and allowed to air dry. Use one-half cup chlorine bleach to one gallon of water as a disinfectant.	Don't allow dirty dishes to accumulate in sink or wash hands over soiled dishes in the sink.
Do give only prescribed medication to a pupil at school following directions from the school nurse. A special form must be completed by the parent/guardian. When medication is given in the class-room, the medicine form must be initialed by the person administering the drug,	Don't give or prescribe unauthorized medication (prescription or over-the-counter) to any student.
Do dispense medication and follow guidelines, (Giving Medications at School - ABC or #1 or #2). Make sure the right child is getting the right medication and correct dosage at the designated time. Pour medication into a container and administer without touching. If necessary, wear gloves (Guidelines for Handling Body Fluids).	Don't touch the medication with your bare hands.
Do mark each toothbrush with pupil's name or some other symbol of identification. Each toothbrush should be allowed to air dry. toothbrushes are provided free from the National Foundation of Dentistry for the Handicapped. They are also available from the school nurse at A nominal fee. Teeth can be brushed using only	Don't use bare hands when assisting with toothbrushing.

DO	DON'T
water. If you choose to use tooth paste, squeeze onto the brush to avoid cross-contamination.	
Do report any dental, gum or mouth problems to the school nurse.	Don't attempt to remove food or other lodge particles from teeth.
Do teach the pupil to care for minor cuts and abrasions by encouraging him/her to wash the area well with soap and water. Bandaids only need to be applied if bleeding persist. In the event of a major accident head injury, possible broken bone, serious cut or bruise, unconsciousness) the parent/guardian should be notified and an accident report completed. These forms are available in the school office. The parent/guardian should be informed of accidents and illnesses by the teacher and/or school nurse.	Don't neglect to report any injuries or illnesses. Don't attempt to move any student with serious injuries.
Do inform teacher, school nurse, and/or principal of any significant injury.	
Be aware of unusual behaviors that may indicate illness. Observe for signs of illness, i.e., rash, fever, persistent cough and runny nose.	Don't touch broken skin injuries or lesions with bare hands.
Do remember to use gloves When touching any body fluids.	
Do identify those persons in the building who are certified CPR (Cardio Pulmonary Resuscitation) providers.	Don't attempt to give CPR if you have not had training.
Do the following in any life-death situation:	Don't leave an injured or illl person unattended.
Do use good common sense. Try to remain calm.	Don't Panic!
Do send someone to the nearest phone to call 911 - ask for paramedic division. Be prepared to give information regarding school address, location of door for quickest access to person in need. Do give description of condition such as having seizure, unconscious, difficulty breathing, bleeding, etc.	

DO	DON'T
If indicated, do administer CPR. If you do not know how to administer CPR, send for someone who does.	
Do notify parent/guardian, as soon as possible, if requested. Refer to emergency card in office for directions outlined by parent/guardian. A school employee must accompany anyone transported by ambulance.	
Be responsible and aware of appropriate clothing indoors and outdoors for students.	Don't allow students to be underdressed or overdressed for environmental conditions.
Do maintain privacy for students when changing clothing, especially if exposing body areas.	Don't change diapers, blouses, shirts, etc. without provision for privacy.
Do review "Seizure Disorders Handout for Teachers (attachment). It is important to know there is no extreme danger to the child and the seizure will be over in a few minutes.	Don't Panic!
Do protect from further injury by placing a soft object under the pupil's head and turning him/her on their side.	Don't place any object or fingers in pupil's mouth.
Do be aware that a few pupils do have multiple, uncontrolled seizure disorders.	Don't allow pupil to bang head on floor or other hard objects.
Seek additional guidance from the school nurse as needed.	
Document type and frequency of seizure(s). Report any concerns to teacher/school nurse.	
INVASIVE PROCEDURES:	
Such as - Catheterizing - Gastrostomy feeding - Suctioning	Don't perform any procedures prior to training.
Do refer to "Guidelines for Special Needs Children"(attachments). Training may differ from Guidelines (attachments) depending on individual pupil's needs. Follow Health Care Plan (attachment) after training is completed.	

SCHOOL STAFF

Seek information from school nurse your personal physician regarding occurrence of contagious and infectious diseases, especially if pregnant or considering pregnancy.	Don't think it can never to you. Don't forget to use good health habits and wash hands frequently. Don't share utensils, equipment or food with students/staff.

Common Sense - Your observations and good health practices are vital to attaining and maintaining good health in the classroom. The pupils depend on us to keep them healthy! Use good common sense. don't be afraid to seek help or to say, "I don't know!

APPENDIX G

SPEAKER HANDOUT: V. HERTEL

To: Directors of Health Departments
Superintendents of Schools
Special Education Directors
School Nurses
County Public Health Nurses

FROM: Daniel Gossert, Director
Family and Community Health Services Division
Victoria Hertel, School Health Nursing Consultant

RE: Information Regarding Do Not Resuscitate (DNR) Agreements

DATE: October 18, 1993

Many questions arise regarding requests by parents not to resuscitate -fragile children who have a medical crisis in the school setting. Such requests present many issues and problems which make it very difficult for the requests to be honored in the schools. Therefore, this statement has been developed to offer information to local school and health personnel as they may develop guidelines in this area.

The Colorado Department of Health (CDH), Family and Community Health Services Division (FCHSD), does not advocate that DNR requests be either accepted or rejected. It is believed that the issues are very complex, that differing values are present, that parents may change their minds, and that school personnel and the school setting are quite different from medical personnel in the medical setting. All of these factors make the consideration of a DNR request a difficult matter. Each DNR request has to be considered individually, and developing guidelines to deal with DNR requests is a formidable task.

When parents request that their child not be resuscitated, many ethical issues arise. Because a school setting is quite different from a medical setting, school personnel are not trained to know how to handle a situation where purposeful lifesaving measures are explicitly withheld. In addition, the impact of a child dying in the school setting under these circumstances is understandably very traumatic to other children in that school setting, as well as to school personnel. While parents' rights not to resuscitate need to be respected, school personnel do not have the training to determine if the situation is a DNR situation. When parents reach a decision not to resuscitate, presumably they have thought through the issue, discussed it with their physician, and are emotionally prepared for the child not to be resuscitated. The same process is not presumed to be the case for school personnel. Resuscitation calls should be made to 911 or whatever emergency medical service agencies exist in the community.

Many medical issues also need to be considered regarding DNR agreements. A family may work out an arrangement with which they are comfortable, and one with which they and their physician have agreed. This arrangement may or may not be agreed with by another physician when a resuscitation situation arises. The backup physician for the emergency medical services may not be comfortable honoring such DNR request, especially without historical information about the child.

Therefore, the attending physician may override the decision of the child's physician. Schools may wish to consider referring parents to the emergency medical service personnel who serve the school, if the parents are considering a DNR request. This can allow for the response team's advance planning with the parents.

There are also many legal questions, including the process under which the parents have made a DNR decision for their child. As with the physicians, if the parents have consulted with an attorney to work out an arrangement, another attorney may not agree with that arrangement. Involved in these discussions is the issue of whether parents have the right to make life and death decisions in regard to their child or, in other words, what are the child's rights in these matters? Did both parents sign the DNR agreement? Most schools that consider a DNR request may certainly wish to consult with the school's attorney. The local school boards may also need to be apprised of the situation.

These statements do not imply that the CDH/FCHSD is making any legal arguments--only to recognize that there are legal rights and legal arguments that are best handled by the attorneys in a DNR request situation. Finally, it is also recognized that parents may change their minds about DNR requests, and that they may do so without revoking any written requests they have made to school personnel not to resuscitate. Whatever the school's decision is regarding DNR, please share that decision with the parents so they are not expecting one course of action and the school does another.

c: Patricia Nolan, Executive Director, Colorado Department Health
William Randall, Commissioner, Colorado Department Education

National Association of

State School Nurse Consultants, Inc.

DELEGATION OF NURSING CARE IN A SCHOOL SETTING

New Demands Nursing Services

Students with special health care needs are placing new demands for services on school districts across the nation. Local school boards are being asked to provide health care staff to perform a level of nursing service not seen before in the school setting. The reasons are four:

1. The trend toward outpatient and homebound treatment rather than treatment in an acute care setting;
2. Advances in medical technology which allow monitoring and health maintenance services outside the confines of acute care institutions;
3. The federal Mandate for mainstreaming of special education students with complex health needs;
4. Parent's expectations regarding their child's right to care in the school setting.

These developments raise issues of educational placement, student safety, and school and professional liability that need to be addressed. In making decisions about educational placement of students with health care needs and who is to provide the nursing service, the primary concern must be for the health and safety of the student. The secondary concern is for the legal responsibility of all involved parties (e.g., the school board, school administrators, school staff and, in particular, the school nurse). School administrators are legally responsible for the safety of all students, and this responsibility includes the provision of required health services by qualified staff. Using non-qualified staff could risk potential harm to students. In addition, administrators must realize non-licensed school staff are liable if they practice nursing or medicine without a license.

Nurse's Responsibility for Quality Care

The nurse's ultimate responsibility is to the patient for the quality of nursing care rendered. If the nurse's decisions on care, and who can safely perform it, are in error, the student suffers. In addition, the nurse can be personally liable and possibly in violation of the nurse practice act, which might precipitate disciplinary action against his/her license to practice.

5/7/90

School district administrators have the responsibility to determine educational placement of the student. Administrators are not responsible for deciding whether or not the required nursing service must be provided by a licensed health care provider. The registered nurse is required to make that decision based on the state nurse practice act.

If another licensed health care practitioner delegates nursing care to a non-licensed individual, while the nurse is responsible for the supervision, then the supervising nurse must make delegation determinations before assuming responsibility for the activity.

Questions About Delegating Care

There are two critical questions involved in delegating and supervising nursing care:

1. Is this a nursing task under the state's definition of nursing?

    Nursing and medical activities are defined by state statute and interpreted by state boards of nursing and state boards of medicine and/or state attorneys general and courts. Based on this definition, the nurse decides whether or not the procedure is one that must be performed by a registered nurse.

2. Can the procedure be rendered by non-licensed school staff under the supervision of a registered nurse?

    Nursing activities not specifically addressed in statute or legal interpretations can be performed by a non-licensed individual if the activity does not require the exercising of nursing judgment and if delegated and supervised by a registered nurse.

Determinations Required in Each Case

Given the above, the delegating and supervising registered nurse makes the following determinations for each student with health care needs and each nursing activity required on a case-by-case basis:

1. The nurse validates the necessary physician orders (including emergency orders), parent/guardian authorization, and any other legal documentation necessary for implementing the nursing care.
2. The nurse conducts an initial nursing assessment.
3. Consistent with the nursing practice act and related regulations of each state's board of nursing, and with his/her assessment of the student, the nurse determines who can be delegated the task-licensed (registered nurse or licensed practical vocational nurse), unlicensed health care provider-or other staff person.
4. The nurse determines the amount of in-service training required for the individual performing the nursing service consistent with the Board of Nursing regulations governing the practice by unlicensed personnel.
5. The nurse evaluates the competence of the individual to safely perform the task prior to delegation.
6. The nurse provides a written care plan to be- followed by the unlicensed staff person.
7. The nurse determines the amount and type of registered nurse supervision necessary.
8. The nurse determines the frequency and type of routine student health reassessment and reevaluation necessary for ongoing safety and efficacy.
9. The nurse provides in the care plan for instances when a change in student condition, performance of procedure or change in other circumstance warrants registered nurse intervention and/or reassessment
10. The nurse determines and requires the amount and type of documentation to be done by unlicensed staff, consistent with the State's nurse practice act and rules promulgated by each State Board of Nursing.
11. The nurse documents activities appropriate to the nursing actions listed above.

If The School Is Not The Best Setting For Care

If the delegating and/or supervising nurse determines that a requested procedure may cause harm or cannot safely and efficaciously be performed in the school setting, the nurse should take the following steps:

1. Write a memo to his/her immediate supervisor explaining the situation in specific detail, including:
    a. The reason the procedure should not be performed in school, and a rationale to support this; or
    b. Recommendations for safe performance of the procedure in the school.
2. Maintain a copy of the memo for the school nurse's personal file.
3. Forward copy(ies) of the memo to one or all of the following as indicated: The State Board of Nursing, the district superintendent, and the state school nursing consultant.
4. Repeat notification that the requested procedure should not be performed in school until resolution of the issue.

An Act

SENATE BILL 92-96.

BY SENATORS Wham, Allison, Bishop, Blickensderfer, Cassidy, Gallagher, Groff, J. Johnson, Leeds, Martinez, McCormick, Mendez, Pascoe, Tebedo, and Traylor;
also REPRESENTATIVES Shoemaker, Chlouber, Martin, Rupert, Swenson, Tanner, Webb, and S. Williams.

CONCERNING PROFESSIONAL NURSES' POWER To DELEGATE NURSING FUNCTIONS.

Be it enacted by the General Assembly of the State of Colorado:

SECTION 1. 12-38-103 (10) (c), Colorado Revised Statutes, 1991 Repl. Vol., is amended to read:

12-38-103. Definitions. As used in this article, unless the context otherwise requires:

(10) Practice of professional nursing means the performance of both independent nursing functions and delegated medical, podiatric, and dental functions, including the initiation and performance of nursing care through prevention, diagnosis, and treatment of human disease, ailment, pain, injury, deformity, or physical or mental condition which requires such specialized knowledge, judgment, and skill involving the application of principles of biological, physical, social, and behavioral sciences as are required for licensing as a professional nurse pursuant to section 12-38-111. "Practice of professional nursing shall include the performance of such services as:

(c) Providing therapy and treatment that is supportive and restorative to life and well-being either directly to the patient or indirectly through consultation with, ~~or through the~~ DELEGATION TO, supervision ~~and~~ OF, OR teaching of others;

SECTION 2. Article 38 of title 12, Colorado Revised Statutes, 1991 Rept[: Vol., is amended BY THE ADDITION OF A NEW SECTION to read:

12-38-132. Delegation of nursing tasks. (1) ANY REGISTERED NURSE, AS DEFINED IN SECTION 12-38-103 (11), MAY DELEGATE ANY TASK INCLUDED IN THE PRACTICE OF PROFESSIONAL NURSING, AS DEFINED IN SECTION 12-38-103 (10), SUBJECT To THE REQUIREMENTS OF THIS SECTION. IN NO EVENT MAY A REGISTERED NURSE DELEGATE To ANOTHER PERSON THE AUTHORITY To SELECT MEDICATIONS IF -SUCH PERSON IS NOT. INDEPENDENT OF SUCH DELEGATION. AUTHORIZED BY LAW To SELECT MEDICATIONS.

(2) DELEGATED TASKS SHALL BE WITHIN THE AREA OF RESPONSIBILITY OF THE DELEGATING NURSE AND SHALL NOT REQUIRE ANY DELEGATEE To EXERCISE THE JUDGMENT REQUIRED OF A NURSE.

(3) NO DELEGATION SHALL BE MADE WITHOUT THE DELEGATING NURSE MAKING A DETERMINATION THAT, IN HIS OR HER PROFESSIONAL JUDGMENT, THE DELEGATED TASK CAN BE PROPERLY AND SAFELY PERFORMED BY THE DELEGATEE AND THAT SUCH DELEGATION IS COMMENSURATE WITH THE PATIENT'S SAFETY AND WELFARE.

(4) THE DELEGATING NURSE SHALL BE SOLELY RESPONSIBLE FOR DETERMINING THE REQUIRED DEGREE OF SUPERVISION THE DELEGATEE WILL NEED, AFTER AN EVALUATION OF THE APPROPRIATE FACToRS WHICH SHALL INCLUDE BUT NOT BE LIMITED To THE FOLLOWING:

(a) THE STABILITY OF THE CONDITION OF THE PATIENT;

(b) THE TRAINING AND ABILITY OF THE DELEGATEE;

(c) THE NATURE OF THE NURSING TASK BEING DELEGATED; AND

(d) WHETHER THE DELEGATED TASK HAS A PREDICTABLE OUTCOME

(5) AN EMPLOYER OF A NURSE MAY ESTABLISH POLICIES, PROCEDURES, PROToCOLS. OR STANDARDS OF CARE WHICH LIMIT OR PROHIBIT DELEGATIONS BY NURSES IN SPECIFIED CIRCUMSTANCES.

(6) THE BOARD HAY PROMULGATE RULES AND REGULATIONS PURSUANT To THIS SECTION, INCLUDING BUT NOT LIMITED To STANDARDS ON THE ASSESSMENT OF THE PROFICIENCY OF THE DELEGATEE To PERFORM DELEGATED TASKS, AND STANDARDS FOR ACCOUNTABILITY OF ANY NURSE WHO DELEGATES NURSING TASKS. SUCH RULES AND REGULATIONS SHALL BE CONSISTENT WITH THE PROVISIONS OF SECTIONS 25-1-107 (1) (ee) AND 27-10.5-103 (?) (k), C.R.S.

SECTION 3. 12-36-106 (3) (q) (II), colorado Revised Statutes, 1991 Repl. Vol., is repealed as follows:

12-36-106. Practice of medicine defined - exemptions

Capital letters indicate new material added to existing statutes; dashes through words indicate deletions from existing statutes and such material not part of act.

from licensing requirements. (3) (q) (II) ~~This paragraph (q) is repealed effective July 1, 1992. Prior to such repeal the exception to licensure requirements set forth in this paragraph (q) shall be subject to review pursuant to the provisions of section 2-3-120, C.R.S., by the sunrise and sunset review committee.~~

SECTION 4. 12-38-125 (1) (i) (II), Colorado Revised Statutes, 1991 Repl. Vol., is repealed as follows:

12-38-125. Exclusions. (1) (i) (II) ~~This paragraph (i) is repealed, effective July 1, 1992. Prior to such repeal, the exception to licensure requirement set forth in this paragraph (i) shall be subject to review pursuant to the provisions of section 2-3-1201 C.R.S., by the sunrise and sunset review committee.~~

SECTION 5. 27-10.5-103 (2) (k) (V), Colorado Revised Statutes, 1989 Repl. Vol., as amended, is repealed as follows:

27-10.5-103. Duties of the executive director - rules and regulations. (2) (k) (V) ~~This paragraph (k) is repealed effective July 1, 1992. Prior to such repeal, the provisions of this paragraph (k) shall be subject to review pursuant to the provisions of section 2-3-1201, C.R.S.~~

SECTION 6. No appropriation. The general assembly has determined that this act can be implemented within existing appropriations, and therefore no separate appropriation of state moneys is necessary to carry out the purposes of this act. It is furthermore the intent of the general assembly that the licensing fee for nurses not be increased to cover the costs associated with this legislation.

SECTION 7. Safety clause. The general assembly hereby finds, determines and declares that this act is necessary for the immediate preservation of the public peace, health, and safety.

Ted L. Strickland
PRESIDENT OF
THE SENATE

Charles E. Berry
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

Joan M. Albi
SECRETARY OF
THE SENATE

Lee C. Bahrych
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES

APPROVED______________________

Roy Romer
GOVERNOR OF THE STATE OF COLORADO

Chapter XIII

RULES AND REGULATIONS REGARDING THE DELEGATION OF NURSING FUNCTIONS

1. Statement of Basis and Purpose

The rules contained in this Chapter XIII are adopted pursuant to authority granted the board by C.R.S. 1985, 12-38-101 et seq., as amended, and specifically pursuant to authority granted in C.R.S. 1992, 12-38-132(6).

The professional nurse is responsible for and accountable to each consumer of nursing care for the quality of nursing care he or she provides either directly or through the delegated care provided by others. Supervision of personnel associated with nursing functions is included in the legal definition of the practice of professional nursing.

3. Definitions: The following terms have the indicated meaning.

3.1 "Board" means the Colorado Board of Nursing.

3.2 "Client" means the recipient of nursing care.

3.3 "Delegation" means the assignment to a competent individual the authority to perform in a selected situation a selected nursing task included in the practice of professional nursing as defined in section 12-38-103(10).

3.4 "Responsible" means the ability to answer for one's conduct and obligations.

3.5 "Supervision" means the provision of guidance and review by a qualified professional nurse *for* the accomplishment of a nursing task or activity with initial direction of the task and periodic inspection of the actual act of accomplishing the task or activity, and evaluation of the outcome.

3.6 "Delegatee" means an individual receiving the delegation who acts in a complementary role to the professional nurse and whom the professional nurse authorizes to perform tasks which the individual is not otherwise authorized to perform.

3.7 "Delegator" means the professional nurse making the delegation; the delegator must hold a current, active license.

3.8 "Accountability" means the state of being responsible, answerable, or legally liable to the board of Nursing for an action.

Criteria for Delegation

4.1 Any nursing task delegated by the professional nurse shall be:

A. Within the area of responsibility of the nurse delegating the task.
B. Within the knowledge, skills and ability of the nurse delegating the task.

C. Of a routine, repetitive nature and shall not require the delegatee to exercise nursing judgment or intervention.

D. A task that a reasonable and prudent nurse would find to be within generally accepted nursing practice.

E. An act consistent with the health and safety of the client.

F. Limited to a specific delegatee, for a specific client, and within a specific time frame.

4.2 The delegatee shall not further delegate the tasks delegated by the professional nurse to another individual nor may the tasks be expanded without the express permission of the delegating professional nurse.

4.3 The professional nurse shall assure that the delegatee can and will perform the task with the degree of care and skill that would be expected of the professional nurse.

5. Responsibility of the Delegator

5.1 The decision to delegate shall be based on the delegator's assessments of the following:

A. Client's nursing care needs including, but not limited to, complexity and frequency of the nursing care, stability of the client, and degree of immediate risk if task is not carried out.

B. Delegatee's knowledge, skills and abilities.

C. Nature of tasks being delegated including, but not limited to, degree of invasiveness, irreversibility, predictability of outcome, and potential for harm ~ ©.

D. Available and accessible resources such as, without limitation, appropriate equipment, adequate supplies and appropriate other health care personnel to meet the client's nursing care needs.

E. The availability for adequate supervision of the delegatee.

5.2 The delegator shall act in accord with policies, procedures, protocols, or standards of care which limit or prohibit delegations by professional nurses in specified circumstances as established by the employer.

5.3 The delegator shall instruct the delegatee in the delegated task and/or verify the delegatees competence to perform the nursing task, as well as how to intervene in any foreseeable risks which might be associated with the task.

5.4 The delegator shall provide appropriate and adeQuate supervision to the delegatee to the degree determined by the professional nurse based on an evaluation of all factors indicated in 5.1.

5.5 The delegator shall evaluate on an ongoing basis the following:

A. The degree to which nursing care needs of the client are being met.

B. The performance by the delegatee of the delegated task.

C. The need for further instruction.

D. The need to withdraw the delegation.

6. Standards for the Accountability of the Delegator

6.1 The delegator shall adhere to the provisions of the Nurse Practice Act and its rules and regulations.

6.2 The delegator is responsible for the decision to delegate and assessments indicated in 5.1.

6.3 The delegator is responsible for monitoring, outcome evaluation, and follow-up of each delegation.

6.4 The delegator is accountable for the act of delegating and supervising.

7. Exclusions from this Rule

7.1 Any person registered, certified, licensed, or otherwise legally authorized in this state under any other law engaging in the practice for which such person is registered, certified, licensed, or authorized.

7.2 Any person performing a task legally authorized by any person registered, certified, or licensed in this state under any other law to delegate the task.

0091n
Adopted 11/18/92

BOULDER COUNTY HEALTH DEPARTMENT
SCHOOL HEALTH PROGRAM

COMPETENCY GUIDELINE FOR DELEGATION

Student/Patient:______________________ School:____________

Delegatee:______________________ Delegator:____________

Date	Criteria	On File	Delegator's Initials	Delegatee's Initials	Comments
	Physician's Authorization				
	Patient's Permission				
	Health Care Plan				
	Specific Care Procedures				
	Directors for Equipment (incl. cleaning/storage)				
	Demonstration Procedure				
	Instruct on Documentation				
	Return Demonstration (incl. documentation)				
	Process to Locate RN				
	First Aid Certificate (recommended)				
	Monitored Demonstrations				
	1.				
	2.				
	3.				
	4.				
	5.				

Delegatee's Signature ______________________ Initials ________
Delegator's Signature ______________________ Initials ________
3CISD #75 4/93

MEDICATION IN THE SCHOOL SETTING

It is recommended that every possible means be taken to give children medication at home. If it becomes necessary for a student to take any form of medication at school, these steps must be followed:

1. A separate written order from the physician to the school stating the student's name, medication, dosage, and time to be given.
2. Medication properly identified and in its original pharmacy labeled container.
3. Written permission by the parents giving the school district authorization to assist with medication.
4. A medication log of when medication was given.
5. Store the medication in a clean, locked cabinet or container.

Without these five legal requirements, medication is not to be administered at school.

Medication can only be legally given by school personnel whom a registered nurse has trained and delegated the task of giving medication.

Procedure:

Identify student.

Identify medication.
Note student's name on bottle.
Note date of medication on bottle.
Note name of medication on bottle.
Note dosage of medication on bottle. Note instructions on bottle for giving the medication.

Compare information on medication bottle with medication record information.

Doctor's order should be attached to medication record or noted to be in file.

Check to see that the medication has not already been given for that day and time by another school person.

Administer the medication to the student as directed.

Record time the medication is given on student's medication record.

Return medication to locked medication cupboard.

Name of delegatee _______________ Name of delegator_____________

Date of instruction_____Initial by instructor and delegatee_____________

Date of return demonstrations (initial each) ____________________

(Procedure was adapted from Woodland Park School District Procedure)

SCHOOL HEALTH PROGRAM
COMPETENCY GUIDELINE FOR DELEGATION OF MEDICATION

School District:________________________________ School:____________________

Delegatee:________________________________ Delegator:__________________

Date	Criteria	On File	Delegator's Initials	Delegatee's Initials	Comments
	Physician's Authorization to give medication				
	Patient's Permission to give medication				
	Health Care Plan (if indicated)				
	Medication in pharmacy labeled bottle				
	Directions for medication storage.				
	Demonstration procedure (how to determine dosage)				
	Instruction on Documentation of medication given (check to see if medication has already been given)				
	Return Demonstration (include				
	Process to Locate RN				
	First Aid Certificate (recommended)				
	Monitored Demonstrations				
	1.				
	2.				

Delegatee's Signature ______________________________ Initials ___________

Delegator's Signature ______________________________ Initials ___________

Individual Health Care Plan Components

Identifying Data
Source of Medical Care
Health Problems List
Description of Illness/Condition
Specific Precautions
Health Care Treatment Plan
- **Schedule**
- **Personnel Trained**
- **Procedure**
- **Physician Written Authorization**

Emergency Information
- **Person(s) To Contact**
- **Back-up Plan**

Transportation Plan
Re-evaluation Date

Wehrer
10119013.FW2

Department of Health Service
Nursing Service

FOR SCHOOL USE ONLY

Calendar to be initialed each time treatment is given.

Pupil's Name ______ Birth Date ______ Grade ______ Room ______

Treatment ______ Time ______

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Aug																															
Sep																															■
Oct																															
Nov																															■
Dec																															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Jan																															
Feb																															■
Mar																															
Apr																														■	■
May																															
Jun																															■

APPENDIX H

SPEAKER HANDOUT: M. LONG

NATIONAL NEEDS ASSESSMENT: STATUS OF DELEGATION IN STATE NURSE PRACTICE ACTS

STATE	RESPONSE *(Revised January, 1994)*
ALABAMA	Teaching only, no delegation or supervision.
ALASKA	"Allows for supervision, delegation, and evaluation of nursing practice."
ARIZONA	Delegation and supervision to auxiliary workers within the scope of their practice, e.g. nurse aides. Dispensing of medications by school personnel under study.
ARKANSAS	Supervision and teaching of "other personnel."
CALIFORNIA	School nurse may supervise ''qualified, designated" school personnel to give physical care to student. Care must be under school nurse. Delegation specifically permitted under "Standards of Competent Performance."
COLORADO	Delegation and supervision to unlicensed personnel permitted.
CONNECTICUT	Has defined scope of allowed delegable activities by nursing specialty.
DISTRICT OF COLUMBIA	By attorney opinion, allows for delegation and supervision.
DELAWARE	Permits delegation, supervision, and teaching.
FLORIDA	Delegation and supervision are not in the statute but may exist in regulations.
GEORGIA	"May teach and supervise." The term "delegation" is not included in broad practice standard to delegate and supervise under appropriate conditions. Teaching and supervision but no mention of delegation.
HAWAII	May teach, supervise, and delegate portions of nursing practice, but if any are improperly performed, the nurse is subject to "professional misconduct."
IDAHO	Position Statement on Role and Responsibility of School Nurse allows delegation and teaching if there is no conflict within the practice act

STATE	**RESPONSE** *(Revised January, 1994)*
ILLINOIS	Supervision and teaching, but no delegation.
INDIANA	Awaiting revision from State Board. Delegation only to nursing aides. Attorneys opinion questions delegation. Legislative amendment likely.
IOWA	"Position Statement" and Act allow for teaching and supervision, but no delegation.
KANSAS	Delegation in school setting of specific tasks. Under review--problems may have arisen.
KENTUCKY	Regulations permit delegation. Supervision, delegation, and teaching in statute definition.
LOUISIANA	Allows for instruction, supervision and delegation based on delegation criteria not tasks.
MAINE	Delegation to LPNs and nursing assistants. Teaching permitted.
MARYLAND	Awaiting revision. Delegation and supervision by declaratory ruling.
MASSACHUSETTS	Teaching, delegation, and supervision (of unlicensed personnel) are permitted.
MICHIGAN	Permits delegation, teaching, and supervision by registered nurses.
MINNESOTA	May be delegated to nursing personnel (broadly defined).
MISSISSIPPI	Delegation allowed within professional judgement of nurse. Teaching, delegation, and supervision in definition.
MISSOURI	Teaching and supervision of unlicensed individuals, but no delegation of tasks.
MONTANA	Teaching, supervision, and delegation are permitted.
NEBRASKA	Permits delegation, teaching; supervision implied.
NEVADA	Teaching, supervision, and delegation are permitted.
NEW HAMPSHIRE	Allows "teaching, direction, and delegation."
NEW JERSEY	No delegation or supervision and teaching of persons by statute.

STATE	**RESPONSE** *(Revised January, 1994)*
NEW MEXICO	By declaratory ruling: May delegate to non-licensed person who is prepared by education and experience to recognize and handle complications that may arise. Statute itself permits teaching and supervision, but does not mention delegation.
NEW YORK	No delegation or supervision, but legislative amendment being sought.
NORTH CAROLINA	May delegate to unlicensed person if six criteria are met (administrative rule). Includes "personal care" in a school setting. Supervision and teaching only contained in Act itself.
NORTH DAKOTA	Teaching, supervision, and delegation are permitted.
OHIO	May supervise and delegate nursing practice.
OKLAHOMA	Delegation, supervision, and teaching allowed.
OREGON	Declaratory ruling regarding unauthorized practice by school aides allowing CIC. Teaching and delegation permitted; supervision of "nursing assistants" allowed.
PENNSYLVANIA	Health teaching permitted. No mention of delegation or supervision in Act itself.
RHODE ISLAND	Teaching, but no delegation or supervision.
SOUTH CAROLINA	Delegation and supervision of routine nursing tasks allowed by interpretation (not meds). Teaching, supervision, and delegation are permitted.
SOUTH DAKOTA	Scope of practice permits teaching, delegation, and supervision. However, aiding or abetting "an unlicensed or uncertified person to practice nursing" is grounds for relocation or suspension of nursing license.
TENNESSEE	"May manage, supervise, and teach..." Defines "adequate supervision" and places within judgment of nurse. Teaching, delegation, and supervision are permitted.
TEXAS	May supervise and delegate. Texas Education Code gives immunity to school personnel administering medications.

STATE	RESPONSE *(Revised January, 1994)*
UTAH	Limited delegation in accordance with guidelines from Practice Issues Committee regarding child with Special Health Care Needs in School Setting. Teaching, delegation, and supervision are permitted by Act.
VERMONT	Delegation and supervision are permitted.
VIRGINIA	Nurse may supervise and teach, but no delegation permitted. Legislative amendment likely.
WASHINGTON	Delegation, supervision, and teaching are permitted.
WEST VIRGINIA	Supervision and teaching are allowed, but not delegation.
WISCONSIN	Delegation and supervision allowed. Under study by task force.
WYOMING	Teaching, supervision, and delegation are permitted.

APPENDIX I

SPEAKER HANDOUT: J. NACKASHI

Academy of Pediatrics COMMITTEE ROSTER 07/19/94
COMMITTEE: Children w/Disabilities

ID#	S	D	NAME	ADDRESS
1023030	0	0	William Joseph Miner MD Chairman 907/279-6661	Alaska Native Med. Center 255 Gambell Street Anchorage AK 99501-6108 1990-1992
163393	2O	O	William G. Watson MD Chairperson Alabama	1919 Montgomery Hwy, Ste A Dothan, AL 36303-2601 0-0
105739	0	0	Gilbert A. Buchanan MD Chairperson Arkansas 501/664-4117	500 S. University Suite 200 Little Rock, AR 0-0
132166	0	O	Vikki Ann Stefans MD Chairperson Arkansas 501/320-4274	Arkansas Children's Hospital South Campus, Room 216 1120 Marshall St. Little Rock, AR 72202 0-0
135639	0	0	Sheila Gahagan MD Chairperson Arizona 602/267-5404	Dept of Pediatrics Maricopa Med. Ctr. 2601 E. Roosevelt Phoenix, AZ 85008-4973 0-0
100409	0	0	Arlean L. H. Downing MD Chairperson California 714/973-1999	2313 N. Old Grand Street. Santa Ana, CA 92701-1611 0-0
111985	0	0	Howard Leiter Wolfinger Jr MD Chairperson California 619/576-2851	San Diego/Imperial Counties Development Services 4355 Ruffin Rd. #205 San Diego, CA 92123 0-0
123453	0	0	Robert A. Jacobs MD MPH Chairperson California 213/660-2450	Children's Hospital of LA 4650 Sunset Blvd Box 53 Los Angeles, CA 90027-6088 0-0
125992	0	0	Janet S. Young Chairperson California 707/833-2810	135 Frey Rd. Santa Rosita CA 95409-6521 0-0
113606	0	0	Edward Goldson MD Chairperson Colorado 303/355-9226	6303 East Sixth Avenue Denver, CO 80220-5311 0-0
131635	0	0	Lawrence Charles Kaplan MD Chairperson Connecticut 203/667-5587	Dir. Disable Child Care Newington Child Hospital 181 E. Cedar Street Newington, CT 06111 0-0

Academy of Pediatrics COMMITTEE ROSTER 07/19/94
COMMITTEE: Children w/Disabilities

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100476	0	0	Susan B. Stine MD Chairperson Delaware 302/651-4506	A.I. DuPont Institute Box 269 Willmington, DE 19899-0269 0-0
136867	0	0	Harry Marcel VonTobel Chairperson Florida 904/399-0101	JaX Dev. Behav. Ped. Serv. 3609 Hendricks Avenue Jacksonville, FL 32207-5311 0-0
116036	0	0	Ronald Dwain Blackston MD Chairperson Georgia 404/321-0111	1652 N. Gatewood Road NE Suite 10 Atlanta, GA 30329-4221 1991-1992
132985	0	0	Michael Hugh Hart MD Chairperson Nebraska 404/727-4036	Emory University Dept. of Peds. 2040 Ridgewood Dr. NE Atlanta, GA 30322 0-0
100427	2	0	Don C. Van Dyke MD Chairperson Iowa 319/353-6135	Div.oF Developmental Disab. Dept. of Pediatrics University of Iowa Hosp. & Clinics Iowa City, IA 52242 0-0
101933	0	0	Evelyn St. Clair MD Chairperson Idaho 208/343-5355	276 W. Ridgeline Dr. Boise, ID 83702-6501 0-0
110047	0	0	Robert F.Diehl MD Chairperson Illinois 217/793-2340	Div. of Specialized Care fo Children P O Box 19481 2815 W. Washington Suite 300 Springfield, IL 62794-9481 0-0
108401	0	0	John R. Poncher MD Chairperson Indiana 219/462-0555	1101 E. Glendale Blvd Valparaison, IN 0-0
111500	0	0	Stephen Christopher Meyers MD Chairson Kansas 316/275-3730	Garden Medical Clinic, P.A. 603 N. Fifth St. Garden City, KS 67846-5635 0-0
108835	0	0	Jeffries L. Blackerby MD Chairperson Kentucky 502/782-8700	1211 Ashley Circle Bowling Green, KY 42104-3383 0-0
136814	0	0	Kathleen Braden MD Chairperson Massachusetts 617/956-5337	750 Washington St. Box 351 Boston, MA 02111-1533 1992-1993

Academy of Pediatrics COMMITTEE ROSTER 07/19/94
COMMITTEE: Children w/Disabilities

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125475	0	0	Donald Barry Kaufman MD Chairperson Michigana 517/353-4584	Dept. Pediatrics/Human Dev. Michigan State University Life Science Bldg. East Lansing, MI 48824-0001 1991-1992
125425	0	0	William Brooks Donald MD Chairperson Minnesota 612/371-1630	2222 Riverside Ave., S. Minneapolis, MN 55454-1321 0-0
123789	0	0	Pasquale J. Accardo MD Chairperson Missouri 314/577-5609	Room 416 Glannon Hall 1465 S. Grand Blvd. St. Louis, MO 63104-1003 1991-1994
100851	0	0	James Edwin Young MD Chairperson Montana 406/232-6513	RR1 Box 2358 Miles City, MT 59301-9224 0-0
123789	0	0	William Carl Cooley MD Chairperson New Hampshire 603/650-7384	Dartmouth Hitchcock Med. Ctr. Genetics & Child Development 1 Medical Center Dr. Lebanon, NH 03756-0002 0-0
852	0	0	Joseph Andrew Holahan MD Chairperson New Jersey 201/977-2177	St. Joseph Hop. & Med. Ctr. Child Development Center6 703 Main Street Peterson, NJ 07503 0-0
132846	0	0	Javier Aceves Chairperson New Mexico 505/272-5200	Carrie Tingley Hospital Dept. of Pediatrics 1127 University Blvd. NE Albuquerque, NM 87102-1701 1990-1992
112066	0	0	Thomas John Scully MD Chairperson Nevada 702/784-6001	University of Nevada School of Medicine Reno, NV 89557-0001 0-0
113608	0	0	Harold Alan Kanthor MD Chairperson New York 716/787-1250	2000 Empire Blvd. Ste. 200 Webster, NY 89557-0001 0-0
101388	0	0	Sonya G. Oppenheimer MD Chairperson Ohio 513/559-4691	Cincinnati Center Developmental Disorders Elland & Bethesda Cincinnati, OH 45229 0-0

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1344481	0	0	Maureen A. Fee MD, JD Chairperson Pennsylvania 215/427-5531	St. Christopher's Hosp. Developental Peds. Front L Erie Drive Philadelphia, PA 19134 0-0
116000	5	0	Charles R. Propst MD Chairperson South Carolina 803/773-6630	30 Buford St. Sumter, SC 29150-4735 0-0
127258	0	0	Quentin A. Humbard MD Chairperson Tennessee 615/647-1313	Children's Clinic 2199 Memorial Drive Clarksville, TN 37043-4451 0-0
122225	0	0	W. Daniel Williamson MD Chairperson Texas 713/666-6266	4500 Bissonnet Suite 350 Bellaire TX 77401-3113 0-0
132932	0	0	Lt.Col. Charles T. Morton MD Chairperson Uniformed Services - West 210/570-7347	WHMC/PSP 2201 Bergquist Drive Suite 1 Lackland AFB TX 78236-5303 0-0
142636	0	0	Susan A. Dilks MD Chairperson Virginia 804/924-8184	Children's Rehabilitation Center 2270 Ivy Road Charlottesville, VA 22903-4972 0-0
873	0	0	John F. McLaughlin MD Chairperson Washington 206/526-2204	4800 Sand Point Way NE P O Box C-5371 Seattle, WN 98105 0-0
139624	0	0	Jack Stephens MD Chairperson Washington 206/388-6002	The Everett Clinic 4410 106th Street SW Seattle, WN 98105-3916
143179	0	0	Sharon Fleischfresser MD Chairperson Wisconsin 414/475-5640	1909 N. 72 Street Wauwatosa, WI 53213-1825 1990-1992
126328	0	0	Anju K. Khanijou MD Co-Chairperson California 714/456-5640	University of CA - Irvine 101 City Drive South, Bldg. 27 Orange, CA 92668-2901 0-0
104896	0	0	Ellis Jay Arnstein MD Co-Chairperson New York 3 718/597-8500	Medical Director 1175 Morris Park Ave Bronx, NY 10461-1915

ID#	S	D	NAME	ADDRESS
109708	0	0	Harriet Coussons MD Co-Chairperson Oklahoma 405/271-5700	1724 Dorchester Drive Oklahoma City, OK 73120-1006 1991-1993
114676	0	0	James G. Coldwell MD Co-Chairperson Oklahoma 918/664-6600	Children's Med. Ctr. P O Box 3564B 5300 E. Skelly Dr. Tulsa, OK 74153-0648 1991-1993
121422	0	0	Monica J. Schaberg MD Co-Chairperson Rhode island 401/434-3400	58 Irving Avenue Providence, RI 02906-4141 0-0
122071	0	0	Louise S. Kiessling Co-Chairperson Rhode Island 401/789-0762	Jerry Brown Farm 110 Fire Lane #1 Wakefield, RI 02879 0-0
123231	0	0	Joel Fontaine Bradley Jr MD Co-Chairperson Tennessee 615/647-8700	2199 Memorial Drive Clarkville, TN 37043-4447 0-0
127882	0	0	Larry Wayne Desch MD Co-Chairperson Wisconsin 608/263-7333	University of Wisconsin Weisman Center 1500 Highland Avenue Madison, WI 53705-2280 1992-1993

APPENDIX J

SPEAKER HANDOUT: S. PHILLIPS

CONCEPT PAPER

ON

DELEGATION

Concept Paper on Delegation

Purpose

The purpose of the National Council formulating this concept paper is to provide to Member Boards a conceptual basis for delegation from a regulatory perspective. It is the position of the National Council that licensed nurses, in accordance with board of nursing requirements, determine the appropriateness of delegating acts from their scopes of practice. Each person involved in the delegation process is accountable for his/her own actions in this process. There is potential liability if competent, safe care is not the outcome of the delegation.

Premises

1. Performance of non-nurse delegated and non-nurse supervised nursing activities by unlicensed persons constitutes practicing nursing without a license and is not in the interest of the health, safety, and welfare of the public.
2. Pieces of care cannot be provided in isolation by unlicensed persons functioning independently of the nurse if the health, safety, and welfare of the public is to be assured.
3. Boards of nursing need to work to assure evidence of adequate nurse involvement where nursing services are being provided and delegated.
4. Boards should promulgate clear rules for delegation in all settings where nursing care is delivered.
5. Boards need to clearly define delegation in regulation.
6. A limited supply of nurses must not be used as an excuse for inappropriate delegation to unlicensed persons.
7. Regulations regarding the delegation of nursing functions must be linked to the disciplinary process.
8. Boards need to pursue criminal prosecution where there is clear evidence that unlicensed persons are performing nursing activities not delegated by nurses.

Premises 1-8 from 1987 "Position Statement on Nursing Activities of Unlicensed Persons."

9. While tasks and procedures may be delegated, the functions of assessment, evaluation and nursing judgement should not be delegated.
10. While non-nurses may suggest which nursing acts may be delegated, it is the licensed nurse who ultimately decides the appropriateness of delegation.
11. The unlicensed person cannot redelegate a delegated act.
12. Boards of nursing must develop clear rules on determination of competence of persons to perform delegated nursing tasks or procedures, the level of supervision necessary, and which acts may be delegated.

Definitions

Delegation
Transferring to a competent individual authority to perform a selected nursing task in a selected situation.

Delegator
The person making the delegation.

Delegate
The person receiving the delegation.

practice area without current competence creates concern about client safety and welfare that is even more critical. The managerial understanding is that the nurse is hired to carry out a specific role on behalf of the employer and that the employer has the authority to assign the nurse as desired. The regulatory perspective holds the nurse accountable for all nursing actions. The licensed nurse has a responsibility not to accept an assignment which the nurse is unable to perform safety. It is important to distinguish the uncomfortable situation where a nurse is expected to work in an unfamiliar setting within the nurse's usual area of practice from the unsafe situation where a nurse is expected to work in a new setting, outside the nurse's usual area of practice, without adequate orientation, education and supervision.

The regulatory perspective should serve as a framework for managerial policies related to the employment and utilization of nurses. Employers may attempt to require nurses to delegate, especially when faced with staffing problems. This is inappropriate when the nurse is not willing to delegate. While employers and administrators may suggest which nursing acts should be delegated and to whom the delegation may be made, it is the nurse who ultimately decides and who is accountable for deciding whether the delegation occurs. If the nurse decides that the delegation may not appropriately or safely take place, then the nurse should not engage in such delegation. In fact, if the nurse decides that delegation may not appropriately or safely take place, but nevertheless delegates, he/she may be disciplined by the board of nursing.

Acceptable Use of the Authority to Delegate

The decision to delegate should be based on the following

- Determination of the task, procedure or function that is to be delegated.
- Staff available.
- Assessment of the client needs.
- Assessment of the potential delegate's competency.
  Consideration of the level of supervision available and a determination of the level and method of supervision required to assure safe performance.

Nurses should avoid delegating practice pervasive functions of assessment, evaluation and nursing judgment. Sometimes there is a differentiation made between the terms "delegation" and "assignment." Delegation involves giving to someone else a task from the delegator's practice. Assignment involves giving to someone else a task within his/her own practice. Based upon this differentiation, the RN would assign acts to other RNs who have the same scope of practice. The RN would delegate to others, e.g. LPNs and unlicensed persons, acts which are within the scope of professional nursing practice. Similarly, the LPN would assign acts within the scope of practice of practical nursing to other LPNs However, the LPN would, if allowed under the State Nurse Practice Act, delegate practical nursing acts to unlicensed persons.

Licensure Accountability

Every nurse is accountable as an individual for practicing according to the statutory mandate in the nurse's jurisdiction of practice. The delegating nurse is accountable for assessing the situation and is responsible for the decision to delegate. Monitoring, outcome evaluation and follow-up are necessary supervisory activities that follow delegation. The delegator is accountable for the act delegated, and may incur liability if found to be negligent in the process of delegating and supervising.

The delegate is accountable for accepting the delegation and for his/her own actions in carrying out the act. If licensed, this person may incur liability if he/she deviates from safe practice through no fault of the delegating nurse.

Boards of nursing may review situations where a delegating nurse made an acceptable delegation to a competent delegate who erred in the performance of the delegated act. Clearly, the delegate is accountable for his/her actions in performing the delegated act. The delegator would be expected to provide supervisory follow-up such as intervention on behalf of the client and corrective action. The delegator would be accountable for the delegation and supervision provided.

APPENDIX K

SPEAKER HANDOUT: S. PHILLIPS AND M. KRAJICEK

Delegation: Invasive Procedures-Children with Disabilities

Presented by
Sally Phillips, PhD, RN, University of Colorado School of Nursing
Marilyn J. Krajicek, EdD, RN, FAAN, University of Colorado School of Nursing

National Council of State Boards of Nursing, Inc.
Annual Meeting Concurrent Educational Sessions
August 3, 1994
Chicago, Illinois

Delegation: Invasive Procedures - Children with Disabilities

Educational Objectives:

The participants will become familiar with the Individuals with Disabilities Education Act as it relates to children.

The participants will examine the issues of delegation of nursing functions related to the care of children with developmental challenges in schools and day care facilities under the mandate of the Individuals with Disabilities Education Act.

The participants will explore the historical progression in Colorado toward a change in the Nurse Practice Act for delegatory authority.

The participants will examine various Nurse Practice Acts across the country related to enabling legislation for delegation.

The participants will explore Mandatory Standards for care of children with developmental challenges.

The participants will have the opportunity to examine a case study where delegation is being safely and successfully implemented.

Presentation Outline:

I. Overview of the IDEA Related to Children

II. Presentation on issues of delegation of nursing functions related to children in schools and day care

III. Presentation of a case study of the evolution of delegation in Colorado

IV. Overview of Nurse Practice Acts related to enabling language for delegation

V. Presentation on Mandatory Standards of care for children with challenges

VI. Present a video of an on-site interview followed by a dialogue on issues of delegation in participants' states related to developmentally challenged children in schools and day care

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DELEGATION: INVASIVE PROCEDURES-CHILDREN WITH DISABILITIES

Due to the proliferation of high medical/health-related technologies, children are surviving who would not have done so twenty years ago (Kohrman, 1992, p.3). As a result of such children living longer, those having medically complex needs and especially those necessitating invasive procedures are increasing in number. This in turn is causing an increased burden on systems, family and society in general (Kohrman, 1992, p.4).

Impact of IDEA

Defining this population of children with special health care needs is most challenging. It includes those with complex medical needs, those who are medically fragile, and those who are technologically-dependent. What is characteristic of these children is that they require an intense level of medical/health-related procedures which involve some type of equipment to effect the procedures. Administering these procedures, termed **invasive procedures**, is beyond the normal capabilities of untrained personnel at all levels (U.S. Congress, 1989, p.31). Under IDEA and federal judicial opinions interpreting the statute's mandates, children with disabilities that affect their ability to receive benefit from education programming are entitled to receive health care services, which are categorized under the Act (Part B) as "related services".

Specific types of identifiable conditions of children in this population might include those dependent on mechanical ventilation, those requiring intravenous medication therapy, those needing new kinds of device-based respiratory or nutrition support such as suctioning tracheostomy care, oxygen or tube feeding (nasal or gastrostomy), those requiring apnea monitors and kidney dialysis, those requiring urinary catheterization and colostomy/ileostomy care, children with such conditions as AIDS (U.S. Congress, 1989, p.32), and closed head injuries.

For lack of a universally understood term, and for purposes of this presentation, all of the above will be included in the term "children with complex medical needs."

With passage of the Individuals with Disabilities Education Act (originally in 1975, amended several times and renamed IDEA in 1990) states must provide early intervention services to infants and young children with special health care needs in regular school, preschool, and child care center settings. This includes the mandate to provide services, including invasive procedures, to children with complex medical needs.

Implementation of the Individuals with Disabilities Education Act requires that we address a number of major issues. According to Gallagher (1992), in fact, IDEA is one law that requires "...a great deal of decision making at the state level...Policy concerning definitions, finance, interagency coordination, family involvement, and other such matters needs to be made before the law can be effectively implemented." (p. 1)

Furthermore, many state leaders are unaware of how their existing legal obligations and constraints (fiscal and legal) impact the implementation of IDEA. According to a report by Long and Smith in a 1991 survey many states' Nurse Practice Acts either prohibited or restricted the delegation of nursing tasks such as invasive procedures to non licensed personnel. A survey currently in process indicates that a number of states have subsequently added delegatory language to either the state's Nurse Practice Act or to the regulations promulgated under the act. Such restrictions significantly impact the ability of school districts and state agencies serving persons with disabilities to adequately and safely meet the medical/health needs of these specialized populations. The conclusion of many survey participants was that both the restrictions of the State Nurse Practice Act and the general shortage of prepared registered nurses negatively impacted compliance with federal mandates in the education settings.

A Consensus committee supported in part by project MCJ-215052 form the Maternal Child Health program (Title V, Social Security Act), Health Resources and Services, in support of the Spirit and Intent of IDEA, developed a "description of nursing's scope of practice and the development of Standards of Practice for Early Intervention Services." (National Standards, 1993).

IDEA has reinforced the need for each state to examine its respective definition of nursing practice and to develop and adopt standards of nursing practice which will permit invasive procedures as related services in compliance with IDEA to be provided. These standards include: 1) providing a safe environment for all children; 2) protecting employers and employees from liability (i.e., school districts, nurses, child care centers and their employees); and 3) serving children in the least restrictive environment possible, which is a mandate of IDEA.

Liabilities concern medical/health professionals who work in early intervention settings as well as the states and agencies in which special services are provided. For example, in schools it is the school nurse, by law, who has responsibility for carrying out procedures for children who present complex medical needs. However, if the school district administrators, or even the nurses inappropriately delegate these tasks to paraprofessionals, the school district, the administrators, and the nurses can all be sued for acts' of negligence.

Three of the major strategies that can be taken to minimize such liability are (Schwab, 1988, p.24):

> Know the laws/standards that apply...(State and Federal)
> Educate policy makers (standards of care; risks) and train providers.
> Establish and update policies, procedures, job descriptions, nursing protocols, and standing orders.

Medication administration is perhaps the most well-known invasive procedure. However, what is not very well-known are the liability issues related to this procedure. As stated in "Legal Issues in School Nursing Practice (Cohn, 1988),

The administration of medications in school settings is governed by law.. Schools without explicit state regulations may develop policies and procedures for administration of medication during school hours ..The malpractice liability of the school nurses well as other school personnel who administer medications, is that of ordinary negligence unless changed by statute. Medication should not be administered at all unless the order for it complies with state and local rules.. Usually a Physician's order and parental consent are required (pp 9-10)

In 1986, a special Health Task Force for Schools was formed in Colorado, representative of a number of agencies concerned with the issues surrounding the child with complex medical needs and invasive procedures. The Task Force was chaired by the Director of Nursing of the Colorado Department of Health. Numerous activities took place from 1986-91 including a needs assessment to determine numbers of children needing invasive procedures enrolled in the education system throughout the state (urban and rural), and meetings with the Colorado Attorney General's office. In addition, the Colorado State School Nurse Consultant met on a number of occasions with directors of Special Education, numerous nursing groups, advocates, parents, etc. to discuss their issues.

The primary issue that was of most critical concern was the interpretation of the Colorado Nurse Practice Act. The Colorado State Board of Nursing, in conjunction with the Colorado Attorney General's interpretation of the Colorado Nurse Practice Act (based on a 1980 Colorado Attorney General's Opinion), did not allow for the delegation of nursing tasks such as invasive procedures (medications, gastrostomy feeds, etc.) to others who did not hold a Colorado Nursing License.

Numerous meetings, activities and efforts, including a presentation to the Colorado State Board of Nursing, continued. School nurses and school paraprofessionals from throughout the state testified at a Sunset hearing regarding a medication aid bill before a summer interim committee of the Colorado Legislature on the concerns and needs of serving children with complex medical needs in the schools. An outcome of these hearings was support for a delegatory clause to be inserted into the Colorado Nurse Practice Act to enable nurses to train, supervise, and delegate nursing tasks to assistive, non-licensed personnel. The Colorado Nurse Practice Act was amended in January, 1992 by the Colorado Legislature and a delegatory clause was added. It was signed into law June 1992 by Governor Roy Romer.

Delegation

The movement to incorporate statutory language to enable nurses to delegate nursing tasks to unlicensed assistive personnel has facilitated the challenging aspects of implementing IDEA for children with complex medical needs in child care and school settings. Until delegatory language was available in Colorado, nurses were excluded from the training and supervision of invasive procedures carried out with these children by paraprofessionals, teachers, and other facility personnel. Before addressing further aspects of a safe team approach to implementing a program of care for children with complex medical needs involving invasive procedures several generally accepted definitions are necessary.

In a Concept Paper on Delegation issued by the National Council State Boards of Nursing (NCSBN,1990), delegation is defined as

> transferring to a competent individual authority to perform a selected nursing task in a selected situation.

Further, in a Position Statement on Activities of Unlicensed Persons (NCSBN, 1987) from the same source, supervision is defined as

> provision of guidance by a qualified nurse for the accomplishment of a nursing task or activity with initial direction of the task or activity and periodic inspection of the actual act of accomplishing

> the task or activity. Total nursing care of an individual remains the responsibility and accountability of the nurse.

In addition in the American Nurses' Association Position Statement (1992) the term unlicensed assistive personnel (UAP) has been defined as

> an unlicensed individual who is trained in an assistive role to the licensed registered nurse in the provision of patient/client care activities as delegated by the nurse. The term includes, but is not limited to nurse aides, orderlies, assistants, attendants or technicians.

Licensure accountability is defined by the National Council State Boards of Nursing (NCSBN, 1990) as

> an individual's responsibility for practicing according to the statutory mandate in the nurses jurisdiction of practice. The delegating nurse is accountable for assessing the situation and is responsible for the decision to delegate. Monitoring, outcome evaluation and follow-up are necessary supervisory activities that follow delegation.

In order to protect the public and provide for the protection of the public's health, safety, and welfare, several premises exist for the implementation of delegation (NCSBN, 1990):

Premises

1. Performance of non-nurse delegated and non-nurse supervised nursing activities by unlicensed persons constitutes practicing nursing without a license and is not in the interest of the health, safety, and welfare of the public.
2. Pieces of care cannot be provided in isolation by unlicensed persons functioning independently of the nurse if the health, safety, and welfare of the public is to be assured.
3. Boards of Nursing need to work to assure evidence of adequate nurse involvement where nursing services are being provided and delegated.
4. Boards should promulgate clear rules for delegation in all settings where nursing care is delivered.
5. Boards need to clearly define delegation in regulation.
6. A limited supply of nurses must not be used as an excuse for inappropriate delegation to unlicensed persons.
7. Regulations regarding the delegation of nursing functions must be linked to the disciplinary process.

8. Boards need to pursue criminal prosecution when there is clear evidence that unlicensed persons are performing nursing activities not delegated by nurses.

   Premise 1-8 from the " 1987 Position Statement on Nursing Activities of Unlicensed Persons."

9. While tasks and procedures may be delegated, the functions of assessment, evaluation and nursing judgement should not be delegated.
10. While non-nurses may suggest which nursing acts may be delegated, it is the licensed nurse who ultimately decides the appropriateness of delegation.
11. The unlicensed person cannot redelegate a delegated act.
12. Boards of nursing must develop clear rules on determination of competence of persons to perform delegated nursing tasks or procedures, the level of supervision necessary, and which acts may be delegated.

For illustrative purposes the Delegatory Clause of the Colorado Nurse Practice (1992) is cited:

> 12-38-132. Delegation of nursing tasks. (1) Any registered nurse, as defined in section 12-38-103 (11), may delegate any task included in the practice of professional nursing, as defined in section 12-38-103 (10), subject to the requirements of this section. In no event may a registered nurse delegate to another person the authority to select medications if such person is not, independent of such delegation, authorized by law to select medications.
>
> (2) Delegated tasks shall be within the area of responsibility of the delegating nurse and shall not require any delegates to exercise the judgment required of a nurse.
>
> (3) No delegation shall be made without the delegating nurse making a determination that, in his or her professional judgment, the delegated task can be properly and safely performed by the delegatee and that such delegation is commensurate with the patient's safety and welfare.
>
> (4) The delegating nurse shall be solely responsible for determining the required degree of supervision the delegatee will need, after an evaluation of the appropriate factors which shall include but not be limited to the following:
>
> (a) The stability of the condition of the patient;
>
> (b) The training and ability of the delegatee;
>
> (c) The nature of the nursing task being delegated; and
>
> (d) Whether the delegated task has a predictable outcome.
>
> (5) An employer of a nurse may establish policies, procedures, protocols, or standards of care which limit or prohibit delegations by nurses in specified circumstances.

(6) The board may promulgate rules and regulations pursuant to this section, including but not limited to standards on the assessment of the proficiency of the delegatee to perform delegated tasks, and standards for accountability of any nurse who delegates nursing tasks. Such rules and regulations shall be consistent with the provisions of sections 25-1-107 (1) (ee) and 27-10.5-103 (2) (k), C.R.S.

Implementation and Adaptation of Delegation for IDEA

IDEA is family focused emphasizing that the child and family have strengths, needs and resources. An Individualized Family Service Plan/Individualized Education Plan (IFSP/IEP) must be established for each child. The interdisciplinary team determines the unique needs of each child and family incorporating the parent or guardian as a primary participant.

The IFSP/IEP accommodates data on many aspects of the needs and concerns for the child, incorporating the child's present physical health status, cognitive, communicative, socioemotional development and adaptive skills based on acceptable objective criteria. This extensive written plan must include the frequency, intensity, and method of delivery of the service, along with the dates for initiating and completing services. (Jenkins, et al, 1994)

Nursing has been identified as 1 of 14 qualified disciplines to be actively involved in the provision of early intervention services as indicated in the National Standards of Nursing Practice in Early Intervention Service (1993). As defined by the law, nursing interventions may include:

> a) the assessment of health status for the purpose of providing nursing care including the identification of patterns of human response in actual or potential health problems; b) provision of nursing care to prevent health problems, restore or improve functioning and promote optimal health and development; and c) administration of medications, treatments and regimens prescribed by a licensed physician.

Nurses providing early intervention services to this population must include in their nursing care:

-Screening and assessing the physiological, psychological, and developmental characteristics of the infant/child and family for early identification, referral, and intervention;

-Planning and coordinating, with the family and the interdisciplinary team;

-Providing interventions to improve the infant/child and family's health and developmental status;

-Evaluating the effectiveness of nursing care rendered to the infant/child and family within an interdisciplinary, interagency framework. (National Standards, 1993)

Nursing's participation in the establishing of an individualized family service plan is crucial to prioritize the health needs and plan the interventions for the child and family. Intervention services for this population may involve many members of the health care team including other licensed health professionals as well as unlicensed assistive personnel (UAP). Children with special care needs are requiring services that are taxing the resources of settings where children are learning and cared for.

In a statement on Delegation of Nursing Care in a School Setting published by the National Association of State School Nurse Consultants, Inc. (Maire, 1993), the primary concern must be for the health and safety of the student. The secondary concern is for the legal responsibility of all personnel involved. The registered nurse is responsible for deciding whether or not the required nursing service must be provided by a licensed health care provider. This decision is made on the basis of the child's needs and the state nurse practice act. It is critical that each nurse carefully examine each situation that ultimately provides for the quality, safe nursing care rendered. The National Association of State School Nurse Consultants (Maire, 1993) suggest two questions involved in the delegating and supervising nursing care:

1. Is this nursing task under the state's definition of nursing?

2. Can the procedure be rendered by a non-licensed school staff under the supervision of a registered nurse?

The premises of delegation set forth by the National Council State Boards of Nursing(1990) along with the National Standards for Early Intervention Services (1993) both provide guidance for nursing's role in the safe use of unlicensed assistive personnel in the provision of services for children with complex health needs including invasive procedures. In addition the National Association of State School Nurse Consultants, Inc. (Maire, 1993) provide guidelines for delegation and supervision in school settings.

Video Interview

A videotaped, on-site interview at one setting where the needs of this population are being addressed, successfully implementing delegation with a clear commitment to safe, legal administration of medication/health invasive procedures will be presented,

Conclusions

As a result of the growing concern for children with developmental disabilities, Public Law 102-119, the Individuals with Disabilities Education Act (IDEA), reauthorized the Education of the Handicapped Act of 1986. Under this law, each state is required to develop a system of services that involve locating, assessing, tracking, and providing educational and health interventions for children from birth to five years old and their families. States may also develop a plan to address the needs of children from infancy through age two.

Child care and school settings are faced with unique challenges to provide both educational and health care services for these children and their families. The law provides for an interdisciplinary approach to identify and meet the needs of these children and their families. Nursing is in a pivotal role to provide leadership to the team on the provision of safe, quality care that involves not only health promotion activities but the acute complex health needs incorporating invasive procedures as well. The entire interdisciplinary team includes first and foremost the parent or guardian but also other licensed and unlicensed providers. Nurses involved with these children and families must not only be knowledgeable of the health needs, the ability levels of those members of the team, as well as about the professional liability issues.

Many states are struggling with the implementation of IDEA. State Boards of Nursing are faced with critical issues of professional nursing practice that include establishing the safe parameters of delegating nursing tasks to unlicensed personnel. Each state presents with unique challenges that must be addressed within a regulatory arena. Not only must we keep abreast of new dimensions of the care of these children but also the professional accountability as well. In a partnership with professional associations, parent and child advocates, and educational systems, the regulation and safe implementation of care for children with complex needs and their families can be achieved.

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APPENDIX L

SPEAKER HANDOUT: B. PRESLER

RECOMMENDATIONS FROM A REPRESENTATIVE OF THE CONSENSUS COMMITTEE WRITING THE NATIONAL STANDARDS OF NURSING PRACTICE FOR EARLY INTERVENTION SERVICES

by Betty Presler, RN, PhD

1. Delegation of nursing tasks should NOT occur as an isolated component of the nursing process.

   a) Every child who requires a nursing intervention (in this case, an invasive procedure) should have a thorough nursing assessment.

   b) An IFSP/IEP or patient health care plan should be developed in collaboration with the family and members of the child's interdisciplinary team. This plan of care must identify: 1) the child's health needs/problems/diagnoses; 2) patient/family goals or outcomes which can be measured at appropriate intervals; 3) interventions which specifically delineate what must be done, how it is to be done, who will do it and when it must be done; and 4) a systematic plan for evaluation.

2. Delegation of nursing tasks should NOT occur unless there is an organized process for assuring the quality of that service.

   a) The nurse who assesses the child must be competent to manage the nursing component of that child's care.

   b) The nurse is responsible for teaching non-nurses how to perform nursing tasks.

   c) The nurse is responsible for monitoring the performance of the person who is performing the delegated task at periodic intervals.

   d) The nurse is responsible for monitoring the effectiveness of the intervention in relation to outcomes/goals identified on the IFSP/IEP or child's health care plan.

   e) The nurse realizes that delegation of nursing tasks does not mean delegation of responsibility/accountability. The non-professional who is performing the nursing task is practicing on the delegating nurse's license. Complete documentation of: 1) teaching provided; 2) return demonstration; and 3) continuous monitoring of both the performance of the person performing the delegated task and patient goals/outcomes related to the delegated task must occur.

3. Delegation of nursing tasks should NOT be encouraged as a single act of a single nurse Each state that has a "delegatory clause" in the Nurse Practice Act should develop a system for quality assurance which includes monitoring and tracking of outcomes across systems of patient populations and care-givers. Examples of important questions that must be answered include:

   a) Are there patterns of unfavorable outcomes across the system that should be investigated?

   b) Are there nursing tasks that should not be delegated?

   c) What are "best approaches" for ensuring ongoing competence of the care-givers performing the delegated tasks?

   d) Should care-givers providing delegated tasks be credentialed and, if so, by whom.

   e) If unfavorable outcomes are identified either as a "singular" or "systems" wide event, who is responsible or has the authority to correct the problem.

   Several options for systems development/monitoring are possible. Monitoring, evaluation and regulation could be: 1) incorporated into federal/state education law or regulations; 2) incorporated into MCH federal or state law or regulations.

4. There is nothing in the National Standards that prohibits delegation. Standards of Professional Performance relating to Collegiality and Collaboration support team work within the context of Quality of Care. general this member of the Consensus Committee would not recommend delegation of an NG tube insertion, NG tube feeding, or administration IVs or IV medications. Children who are ventilator dependent certainly require frequent assessment and monitoring by a professional nurse although many tasks, i.e. suctioning, can be delegated in a carefully monitored situation.

These recommendations were drafted by Betty Presler and do not necessarily reflect the opinion of the entire Consensus Committee. Their input will be obtained and forwarded to the Advisory Committee.

APPENDIX M

SPEAKER HANDOUT: J. SHACKELFORD

LEAD AGENCIES FOR THE CHILD CARE AND DEVELOPMENT BLOCK GRANT

STATE	DESIGNATED AGENCY
ALABAMA	Human Resources
ALASKA	Community and Regional Affairs
ARIZONA	Economic Security
ARKANSAS	Human Services
CALIFORNIA	Education
COLORADO	Social Services
CONNECTICUT	Human Resources
DELAWARE	Health and Social Services
DISTRICT OF COLUMBIA	Human Services, Early Child Development
FLORIDA	Health and Rehabilitative Services
GEORGIA	Human Resources
HAWAII	Governor's Office of Children and Youth
IDAHO	Office for Children
ILLINOIS	Children and Family Services
INDIANA	Human Services
IOWA	Human Services
KANSAS	Social and Rehabilitation Services
KENTUCKY	Social Services
LOUISIANA	Social Services
MAINE	Human Services, Child Care Coordination
MARYLAND	Human Resources
MASSACHUSETTS	Heath and Human Services
MICHIGAN	Social Services, Children and Youth Services
MINNESOTA	Human Services
MISSISSIPPI	Human Services, Children and Youth
MISSOURI	Social Services, Division of Family Services
MONTANA	Family Services

STATE	DESIGNATED AGENCY
MONTANA	Family Services
NEBRASKA	Social Services
NEVADA	Human Resources, Child Care Service Bureau
NEW HAMPSHIRE	Health and Human Services
NEW JERSEY	Human Services
NEW MEXICO	Human Services
NEW YORK	Social Services
NORTH CAROLINA	Human Resources
NORTH DAKOTA	Human Services
OHIO	Human Services
OKLAHOMA	Human Services
OREGON	Human Resources
PENNSYLVANIA	Public Welfare
RHODE ISLAND	Human Services, Office of Child Care
SOUTH CAROLINA	Health and Human Services Finance Commission
SOUTH DAKOTA	Social Services
TENNESSEE	Human Services
TEXAS	Human Services
UTAH	Human Services, Office of Family Supports
VERMONT	Social and Rehabilitation Services
VIRGINIA	Day Care and Early Childhood Programs
WASHINGTON	Social and Health Services
WEST VIRGINIA	Health and Human Services
WISCONSIN	Health and Social Services
WYOMING	Family Services

*Prepared by NEC*TAS - October 1991*

APPENDIX N

SPEAKER HANDOUT: D. STOCKFORD

National Association of State Directors
of Special Education

Creating Solutions Through State Partnerships in Special Education

NASDSE's Commitment for the 90s

The National Association of State Directors of Special Education (NASDSE) is committed to facilitate the achievement of the following by the Year 2000:

The needs of ALL children are identified and met without reference to assigned labels or categories of severity of disability;

Schools will provide family-focused, one-stop support that includes multi-agency responsibility for:

- information, referral and follow-up systems;
- comprehensive health-care, child care and intervention services; and
- effective preschool learning opportunities to support ALL infants, toddlers, young children and their families.

Schools will provide comprehensive preparation for adult life which includes:

- internship and mentorship programs;
- multi-levels of school-exit points that are outcomes-based; and
- educational attendance options, e.g., unlimited educational leave to prepare ALL students for existing and potential post-secondary options.

Schools will treat diversity as a strength by including:

- parents as full partners in the education of their children;
- mastery learning in outcomes-based curricula; and
- full range of technology support so that instruction is adapted to the natural variability of ALL learners.

Schools will provide learning that is never ending, including:

- community volunteer programs;
- life-long learning options; and
- cross-generational learning environments that make education a life-long experience for ALL learners.

Schools will provide multi-agency community-based services, including:

- counseling;
- recreation; and
- rehabilitation so that the learning environment will be a safe place for ALL learners.

Federal, state and local governments provide adequate funding to meet the needs of ALL students.

NASDSE's Mission & Objectives

The National Association of State Directors of Special Education (NASDSE) promotes and supports education programs for students with disabilities in the United States and outlying areas. NASDSE is a not-for-profit corporation that has been promoting educational services for students with disabilities since 1938.

NASDSE Mission. NASDSE operates for the purpose of providing services to State agencies to facilitate their efforts to maximize educational outcomes for individuals with disabilities.

Association Objectives. All NASDSE activities relate to the following objectives:

1. To expand the capabilities of State Education Agencies (SEAs) to assure successful adult outcomes for individuals with disabilities.
2. To provide effective leadership in the development of national policy related to services which produce those successful outcomes.
3. To be the best national source of information regarding education for individuals with disabilities.
4. To create and maintain a productive and supportive work environment for NASDSE staff through an organizational plan designed to meet NASDSE priorities.
5. To become financially stable and develop resources sufficient to provide essential services to the membership and to achieve our mission and goals.

NASDSE Membership. NASDSE's membership includes the State Directors of Special Education and other persons employed and/or designated by the SEAs, who have specific responsibility for directing, coordinating or supervising programs and services regarding the education of students with disabilities. NASDSE membership extends to the 50 States, the District of Columbia, Puerto Rico, Bureau of Indian Affairs, and the other Federal jurisdictions designated in IDEA.

NASDSE also has affiliate memberships including past SEA members of NASDSE, former employees of State special education programs, staff of local education agencies, college and university faculty and researchers, parents, advocacy group members, lawyers, teachers and students.

The Association is governed by an elected Board of Directors of eight persons, consisting of the President, President-Elect, Secretary-Treasurer, Immediate Past President, and four members-at-large. Board members are elected at the annual meeting held each November.

The Board provides guidance and direction on Association activities, following policy decisions made by the membership at the annual meeting. With member input, the Board develops position statements on issues of national significance.

NASDSE: The Organization

Resources and Facilities. NASDSE established its national office in Washington, D.C. in 1972, and moved to its current quarters in Alexandria, Virginia in 1991. Its office, which includes a conference room convenient for meetings, is near National Airport, and is close to the Metro for easy access to the entire metropolitan area.

NASDSE maintains a private library of resources including current State special education laws and regulations, State Plans and Annual Performance Reports on the Implementation of the IDEA, data analyses, and related policy materials. This information is used to respond to inquiries, to generate analyses of State policy on specific topics, and to assess the impact of emerging issues or potential revisions in Federal regulations or statutes. NASDSE is in the process of compiling a database of State rules and regulations and State plans for special education.

NASDSE has a highly professional staff of experienced special educators, researchers, State and local administrators, policy analysts, and advocates who have extensive experience with the education of children with disabilities.

Staff members are familiar with current national education trends and policy issues. They maintain a link with emerging issues as they arise from Federal, State and local sources around the country. A quick response system can contact all SEAs when critical input is needed or when States must be alerted to fast-breaking events.

Washington, D.C. Liaison. With headquarters in the Washington, D.C. area, NASDSE maintains close contact with key committees of Congress, the Office of Special Education and Rehabilitative Services, and the Office of Special Education

Programs as well as other related offices in the U.S. Department of Education. In addition, NASDSE has established close working relationships with a variety of education and human service organizations, university-based research and information centers, and other national professional and advocacy organizations.

NASDSE has been at the forefront in initiating debate and developing national policy concerning the education of individuals with disabilities and in representing State special education administrators' perspectives in Washington. NASDSE has recently published *Leading and Managing for Performance: An Examination of Challenges Confronting Special Education.* In this document, NASDSE proposes a role for special education in current educational reform efforts.

Contracted Services. NASDSE offers individually designed services to State Education Agencies, recognizing that the States share certain problems and that solutions for one often can be adapted to the needs of others. Contractual services support State administrators, as well as their colleagues at universities, advocacy organizations, and local and regional education agencies, in such areas as needs assessment, data analysis, monitoring and program review, policy development, fiscal analysis, staff development, information services, and development of training materials.

NASDSE's services are delivered through workshops, action seminars, topical presentations, reports, telephone and on-site consultations, legal institutes, and meetings with state advisory committees, task forces and interagency councils.

Current Projects & Initiatives

NASDSE is engaged in the following special projects and initiatives that support its mission and provide services to the membership.

Networking System for Training Education Personnel (NSTEP). This project provides technical assistance and training to SEA staff coordinating the Comprehensive System of Personnel Development (CSPD). The project addresses promising practices and issues in preservice and inservice education, recruitment and retention, licensure and certification, and Federal data collection requirements as they relate to special education teachers, general education teachers, leadership personnel, and related services personnel.

National Information Action Center (NIAC). This project is assessing the critical information needs of State Directors of Special Education in an effort to enhance the administrative competency of State Directors and other SEA personnel; advance state-of-the-art dissemination of information critical to administrators at the State level, and encourage Federal support for future research in the areas where information needs remain unmet.

NCF/NASDSE Technology Partnership. The partnership between the National Cristina Foundation (NCF) and NASDSE is focused on improving adult outcomes for students with disabilities through the use of technology. NCF facilitates this goal through acquiring technology that has been replaced in the business sector and making it available to schools through State Departments of Education. NASDSE's role is to facilitate the linkage between NCF and State Directors of Special Education.

Project FORUM. This project, a contract with the Office of Special Education Programs, identifies information needed to improve the management, administration, delivery and effectiveness of education programs and services, and promotes utilization of research data and other information for improving outcomes for infants, toddlers, children and youth with disabilities. *Project FORUM* provides information on emerging issues, studies critical issues, maintains a library of State policy documents, and convenes small work groups to gather expert input related to specific topics.

Clearinghouse for Professions in Special Education. NASDSE operates a subcontract with the Council for Exceptional Children to fulfil a portion of the work for the *National Clearinghouse for Professions in Special Education.* The Clearinghouse disseminates information on career opportunities, personnel needs, retention of qualified personnel, and sources of financial assistance for special education and related services professionals. The Clearinghouse also supports and facilitates networking among local and State education agencies, professional associations, and institutions of higher education.

Outcomes Project. This project provides assistance to the National Center on Educational Outcomes in developing a conceptual model of outcome indicators and the use of outcomes measurement for students with disabilities. The project also is monitoring national school reform initiatives and developments pertaining to the National Goals especially as they relate to outcomes assessment for students with disabilities.

Early Childhood Services. NASDSE has a subcontract with the *National Early Childhood Technical Assistance System (NEC*TAS)* coordinating office at the Frank Porter Graham Center in Chapel Hill, North Carolina. The *NEC*TAS* project at NASDSE provides information and technical assistance to Part H staff, staff of funded preschool projects, Interagency Coordinating Council members, and Part B - Section 619 staff related to programs and services for young children with special needs from birth through 5 years of age.

Deaf Education Initiative. This project develops models of national standards for programs serving students who are deaf or hard of hearing, for training and credentialing of professional and support personnel, and for competencies for use by interpreter training programs. The project also is identifying and disseminating exemplary State policies and concept papers relevant to State and local administrators.

Information Services

NASDSE's information services keep State Directors informed on important topics as they emerge, and assist each SEA in becoming the focal point for dissemination of data to local education agencies, parents and members of the profession within their States. NASDSE's information services include:

Action Seminars. NASDSE addresses emerging critical educational issues with its action seminar program, made possible through a series of technical assistance agreements with SEAs. The products of the seminars are disseminated nationally. Action seminars combine a presentation of up-to-date information, a discussion of issues, and a list of recommendations for effective program administration.

SpecialNet. NASDSE developed *SpecialNet* in 1981, in order to provide special educators with an efficient, inexpensive, and quick response system for communicating with each other and for accessing current information about the education of children with disabilities. Administered by GTE Education Services, *SpecialNet* is the nation's largest special education-oriented computer communication network connecting more than 3,500 individuals, organizations, and agencies in all 50 states, the U.S. territories, Canada and other countries with 58 topical bulletin boards, 50 databases, and electronic mail. Many SEAs have established user networks and electronic bulletin boards for communication within their State. NASDSE manages the Federal Bulletin Board, and the Early Childhood, Supply/Demand, and CSPD Bulletin Boards.

Liaison Bulletin. NASDSE periodically publishes *Bulletins* reporting on a variety of current topics including legal issues, Federal policy development, special populations, and resources for special educators. The *Bulletin is* disseminated to all State Directors of Special Education, affiliate members, and other interested persons.

Counterpoint. NASDSE publishes a national quarterly newspaper circulated to more than 120,000 State policy makers, local special education administrators, parents, and special educators. Informative and timely articles describe promising practices in special education that affect programs and services for children with disabilities. Each issue presents a round-up of special education news from States and descriptions of new products and publications.

HOW TO JOIN NASDSE

If you are interested in special education, contact NASDSE. A NASDSE membership helps you grow along with the profession. As a member of the NASDSE team, you have the opportunity to:

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Martha J. Fields, Ed.D.
Executive Director
National Association of
State Directors of Special Education
1800 Diagonal Road, Suite 320
Alexandria, VA 22314
Telephone: (703) 519-3800
TDD: (703) 519-7008
Fax: (703) 519-3808
SpecialNet: NASDSE

APPENDIX O

ANNOTATED BIBLIOGRAPHY: NEC*TAS RESOURCES

MATERIALS AVAILABLE FROM NEC*TAS[1]

1) *Key State & Jurisdictional Early Childhood Program Personnel: A Reference for EEPCD Outreach Projects* (November, 1993)
Provides a listing of contact information of Part H Coordinators, Sec 619 Coordinators, CSPD Coordinators, and NDN Facilitators for state and jurisdictions who may be interested in the services of EEPCD Outreach Projects.

- Early Childhood Program Infant and Toddler Program Coordinator for Part H of IDEA;
- Preschool Special Education Coordinator for Part B-Section 619 of IDEA;
- Comprehensive System Personnel Development (CSPD) Coordinator(s) for Part B and, where applicable, for Part H of IDEA (Coordinators are responsible for implementing their jurisdiction's plan as defined in its plan for Part B or Part H of IDEA including procedures for acquiring and disseminating to teachers, administrators, and related services personnel significant knowledge derived from education research and other sources; and...procedures for adopting, if appropriate, promising practices, materials and technology, proven effective through research and demonstration) ; and,
- National Diffusion Network (NDN) State Facilitator. NDN, a program sponsored by the Office for Educational Research and Improvement (OERI) of the U.S. Department od Education, identifies successful programs and practices, disseminates information about them nationwide, and assists schools and other education providers in implementing them. The NDN funds Developer Demonstrator Projects (educational programs deemed effective by the Department of Education's Program Effectivness Panel (PEP), or its predecessor, the Joint Dissemination Review Panel (JDRP), awarded funds to make others aware of their projects and to provide training, materials and technical assistance to support their adoption) and State Facilitator Projects (funded in each state or jurisdiction to disseminate approved programs to schools to meet the needs and interests of educators in their jurisdictions and assist with the adoption of proven programs by making necessary arrangements for training, follow-up, and evaluation of adopted programs.)

Abstracts of Early Education Programs for Children with Disabilities (EEPCD)

EEPCD Inservice Training Projects: Provides contact information and abstracts including purpose, target, approach and outcomes of projects.

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[1] NEC*TAS (National Early Childhood Technical Assistance System)
Frank Porter Graham Child Development Center
University of North Carolina
Chapel Hill, NC 27516
FAX 919-966-7463

Examples include:

- Medically Fragile Inservice for Related Services Team (M-FIRST), the Oregon Health Sciences University & University of Washington
- Project TEAM: The Related Services Team in Community Settings, Teaching Research Division, Western Oregon State College
- NICU Transition project, Experimental Education Unit, University of Washington/Seattle.
- Innovations for Meeting Special Problems of Children with Severe Handicaps in the Context of Regular Education Settings, Department of Special Education, University of Kansas
- Utilization of Innovative Practices for children with Severe Handicaps, College of Education, University of Washington

EEPCD Outreach Projects: Provides contact information and abstracts including purpose, target, approach and outcomes of projects focusing on Least Restrictive Environment/Inclusion.

Examples include:

- Including Young Children with Disabilities in Community-Based Programs: A Three-Tiered Approach, Special Education Services Unit, Colorado Department of Education.
- Community Inclusion Outreach Project, Division of Child and Family Studies, UCONN Health Center
- Project CIP: Community Integration Project, George Washington University
- Project TLC: Technology-Learning-Collaboration National Outreach Project, United Cerebral Palsy Associations, Inc. (Washington, DC)
- PPT: Preschool Preparation and Transition Outreach Project, Department of Special Education, University of Hawaii at Manoa
- Inclusion through Transdisciplinary Teaming, Idaho Center of Developmental Disabilities, University of Idaho
- FACTS/LRE (Family and Child Transitions into Least Restrictive Environments), Department of Special Education, University of Illinois
- Best Practices in Integration Outreach Project (BPI-O), Wright School of Education, Indiana University
- Bridging Early Services Transition project- Outreach, Associated Colleges of Central Kansas (McPherson, KS)
- The CAPPS (Comprehensive Model of Appropriate Preschool Practices and Services) Outreach Project, Kansas University Affiliated Program (Parsons, KS)
- Project SLIDE --Skills for Learning Independence in Diverse Environments, Juniper Gardens Children's Project, University Kansas
- BEACON Outreach Project, Early Recognition Intervention Network (Dedham, MA)
- Project Dakota Outreach, Dakota, Inc.(Eagan, MN)

- Project Coach Outreach: Transdisciplinary Consultation/Coaching Training for Implementing Model Programs, University of Southern Mississippi
- Missouri-TIKES: Training Individuals to Care for Exceptional Students Outreach Project, University of Missouri
- Educational Home Model Outreach Project, Montana University Affiliated Rural Institute on Disabilities, University of Montana
- Project Ta-kos, Alta Mira Specialized Family Services (Albuquerque, NM)
- Charlotte Circle Outreach, Department of Teaching Specialties, University of North Carolina
- Teaching Research Integrated Preschool (TRIP) Model, Teaching Research Division, Western Oregon State College
- Project SUNRISE (Systematic Use of Newly Researched Interventions by Special Educators), Allegheny-Singer Research Institute (Pittsburgh, PA)
- Eliminating Boundaries through Family-Centered, Developmentally Appropriate Practices for Preschool and Primary Children with Disabilities, Special Education Department, Region IV Education Service Center (Houston, TX)
- Multi-Agency Project for Preschoolers (MAPPS) Outreach, Center for Persons with Disabilities, Utah State University
- Statewide Replication of a Model for Early Childhood Special Education Program Development in Rural Settings, Center for Developmental Disabilities, UAP of Vermont, University of Vermont
- SpecialCare Outreach, Williamsburg Area Child Development Resources, Inc. (Lightfoot, VA)
- Portage Multi-State Outreach Project, Cooperative Educational Services Agency (Portage, WI)
- Beach Center on Families and Disability, University of Kansas (Lawrence, KS)

*NEC*TAS (National Early Childhood Technical Assistance System)*

Document describes goal and roles of NEC*TAS and its consortium membership consisting of University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Center (prime contractor) and five subcontractors and Collaborators (Georgetown University Development Center and UAP, ZERO TO THREE/National Center for Clinical Infant Programs (NCCIP), the Federation for Children with Special Needs, the National Association of State Directors of Special Education (NASDSE), and the UAP at the University of Hawaii at Manoa. The project designs and provides technical assistance to Part H staff, Interagency coordinating Council members, Part B - Section 619 staff, and Early Education Program for Children with Disabilities (EEPCD) project staff, as well as various secondary populations.

Resources from the National Early Childhood Technical Assistance System

Document includes lists and ordering information for publications developed under the NEC*TAS contracts and those developed under earlier technical assistance programs (TADS, START, WESTAR) in seven topics: 1) Cultural competence, diversity, and special populations; 2) Evaluation; 3) IDEA and EEPCD; 4) Public awareness; 5) Services to children and families; 6) State and local planning; and, 7) Technical Assistance and Training.
Vendors include: ACCH; DEC; ERIC; NEC*TAS; NCRTM; PACER; Pro-Ed; and ZERO TO THREE.

Overview to Telecommunication Networks

Document describes MCH-Net (the Maternal and Child Health Network Project focusing on mothers and children with special needs), SCAN (Shared Communication and Assistance Network linking communication and resources related to services for persons with disabilities), and SpecialNet (collaborative project of GTE Education Services and the National Association of State Directors of Special Education, nationally linking school districts, state education agencies, parents, professionals and others interested in special education. Topics and services are described and contact information is provided.

Regional Resource and Federal Resource Center (RRFRC) Newsletter

A copy of the first edition newsletter produced by the Federal Resource Center for Special Education provides an overview to the mission and structure of the RRFRC Network and assistance to states by region, as well as RRC publications and products. Contact information for each Region (and lists of the states served by each) is included.

National Head Start Bulletin (Excerpts)

Document lists *Head Start Resource Access Projects (RAPs)*, providing contact information for each region's TASC, RAP, and Teaching Center.

Child Care and the Americans With Disabilities Act (prepared by The Arc, a national organization on mental retardation)

Document addresses basic questions such as the intent of ADA, definitions, impact, and available resources for child care centers. Useful contact information for numerous agencies is provided.

Private Foundations

This document lists and describes five private foundations providing contact information, a synopsis of the foundation's history, target, scope, and programs. The foundations are: a) The Robert Wood Johnson Foundation; b) AT&T Foundation; c) W.K. Kellogg Foundation; d) Danforth Foundation; and, e) United Way of America

Resources for Supporting Inclusion

This document was prepared by NEC*TAS for the National Conference INCLUSION: Making the Dreams Happen (Scottsdale, AZ, September, 1993). It is compiled listing of inclusion-related publications, videos, and training materials. Eighteen videos and 16 training resources are described and contact information is provided. Miscellaneous resources described include publications (books, manuals, catalogs, etc.) for administrators, educators, and others.

APPENDIX P

REPRINTED ARTICLES

Articles

Guidelines for Working with Students Having Special Health Care Needs

J. Carolyn Graff, Marilyn Mulligan Ault

ABSTRACT: *Students with special health care needs present challenges to persons involved with their education, but school staff are accepting the challenge to create safe, nurturing, and stimulating environments for these students This article proposes guidelines for school staff working with students having special health care needs. The guidelines evolved from the authors experiences and are child-related, family-related, and school-related. Discussion of each guideline includes illustrations of issues arising from them. Considerations for implementing the guidelines are presented and include discussion of school policies end procedures and state laws end regulations related to school staff working with students having special health care needs.* (J Sch Health. 1993;63(8):335-338)

For most children, providing health care involves responding to acute or episodic occurrences of trauma or childhood diseases. Most situations can be managed successfully at home, through guidance and intervention by health care professionals. Episodic illness generally are not severe and run their course with the child returning to normal functioning. During these episodes, the student is acutely ill, implying the short term nature of the illness.

Many children, however, experience long-term problems. These conditions may require provision of special health care procedures and affect the children's ability to participate fully in activities at home and school. These children usually are identified by health professionals as having a chronic illness. Approximately 10% of all children have a chronic illness; 2% are severely affected.[1]

Terms such as medically fragile, medically complex, technologically dependent, and children with special health care needs describe and categorize these children. "Children with special health care needs" is used here because of its emphasis on the child, with special health care needs secondary to the child's overall needs.[2] The other terms imply how the medical community views intervention and outcome for these children.

Conditions requiring special health care may include hereditary diseases such as cystic fibrosis, muscular dystrophy, or sickle cell anemia; congenital disorders such as spina bifida or cardiovascular disorders; respiratory disorders such as asthma or recurring pneumonia; neurologic disorders such as cerebral palsy, seizure disorders, or some hearing impairments, cancer such as leukemia; or certain infectious conditions such as human immunodeficiency virus, herpes, or cytomegalovirus. Conditions from childhood trauma, such as traumatic head injury, also may be involved.

The impact of health disorders on students depends on several factors including number of disorders; frequency of acute illness episodes; severity level; overall stability; whether the disorder is degenerative; and impact of the disorder on mobility, cognition, and management of self-care. Even with such variability more similarities than differences exist among these children. An estimated 15% of issues surrounding special health care needs are specific to the condition, while 85% of issues concern the general cause of the chronic health disorder.[3]

Children with special health care needs have more similarities than differences with their peers. They present schools with the same need for engaging, engendering, and safe environments, caring and supportive teachers, and an educational program that promotes development of each student's potential. They also may present school staff with situations to be addressed daily, routinely, and often on an emergency basis. The following guidelines will help school staff in serving students with special health care needs and their families.

1. The child with special health care needs, as with all children, should be regarded as a child who will grow, learn, make friends, and develop skills and abilities.

This right—the right of all children—includes opportunities for new experiences, to learn new skills and new ideas, to make friends, to play, and to develop socially, emotionally, and spiritually. Presumptions for placement should, therefore, first be with their typical peers. Rarely should the health condition restrict the range of experiences for a child. For example, a child with a tracheostomy attends regular kindergarten where

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staff learn to manage care of the tracheostomy. This child communicates with peers and kindergarten staff using sign language, while learning and developing with his peers, and forming friendships.

2. Since the child with special health care needs has periods of better or worse health, view changes in health in terms of usual childhood illnesses rather than immediately attributing changes to the underlying health problem.

These children may have illnesses such as measles, mumps, chicken pox, and colds, as do other young children. Health examinations for usual childhood illnesses should occur periodically. Avoid attributing all health related behavior to the underlying condition necessitating special care. For example, more seizures may occur as a child becomes ill with an infection and develops a fever or an acute illness.[1]

Children with limited communication and limited cognitive skills pose challenges. Caregivers must rely on observations and interpretations of the child and the child's behavior for indicators of problems and not on the more obvious signs and complaints. Before concluding major changes should be made in the child's health care, ensure that typical childhood illnesses are not causing the problem.

3. Give attention to the impact of health-related factors on the child's ability to function in the class-room, home, and community.

School staff should understand the child's health status, behaviors, and concerns related directly to the health condition. School staff should plan for the "what ifs," emergency situations or potential problems related to a child's health condition such as identifying behaviors indicating impending seizure, considering factors that may precipitate a seizure, and planning what to do if a seizure occurs.

For example, if a child starts a new medication, school staff should know a new medication has been started, as well as potential side effects and interactions with current medications. Parents and health professionals should provide written information about any new medication or treatment plan. School staff, conversely, can provide information to health professionals about side effects of a medication or the impact of a medical treatment plan on a child's behavior.

Recognizing and reinforcing a child's strengths requires school staff to "see" beyond the tubes, technology, and health problems to the child's abilities. Training specific to equipment and procedures help minimize staff's anxiety about meeting the needs. For example, a child receives a gastrostomy tube because of minimal weight gain. As nutritional status improves, the child becomes more responsive to persons and the environment. Although school staff initially were uncomfortable managing the gastrostomy tube and feedings, they accept care of the tube and focus on the child's improved responsiveness.

4. Each family's unique approach to their child's health should be acknowledged and respected. Approaches to health should be considered as evolving from various perspectives including family, geographic region, culture and ethnicity, and socioeconomic perspectives.

Families typically do not consult health care professionals first when solving problems and making decisions about health.[4] People talk with members of their family, friends, neighbors, and coworkers. Geographic location also may influence the family's approach to health depending on availability of resources and support.[5,6] Relocation to a different area presents new challenges as they look for assistance and support similar to the previous location.[5]

Perceptions of health also vary among cultural groups.[6] Yet, avoid stereotyping family beliefs and practices as "typical" for a particular group. In addition, avoid assuming characteristics attributed to a group apply to one family. Some families may continue a health practice unique to their culture from generation to generation, while others adopt new practices or modify traditional practices. For example, a family member may use tea and spices to treat illness, while also administering prescribed medications.

The family's involvement with their child's health may vary depending on education and socioeconomic circumstances.[7] Some families may choose others to oversee care rather than being the primary caregiver. School staff can help identify resources heretofore unknown to a family.

5. Parents should be recognized for their important role as experts on their child—experts in maintaining their child's health and conducting activities that promote health.

Parents possess a wealth of knowledge about their child. They know strategies that have been tried, those that work, and those that do not work. They have discussions with their child's pediatrician, pediatric specialists, and other health professionals. Parents sometimes coordinate their child's care, linking all aspects of care. They often educate school staff on special health care procedures unique to their child.[8]

For example, on learning that a child's appointments with health care professionals caused school absences, school staff changed their approach to one child and family. Staff's previous perspective that the family did not value school was replaced with the perspective that the family was extremely busy. Staff worked around the child's schedule and found opportunities to accompany the family to appointments.

The child's educational program was changed to meet the child's needs as staff gained insight about the child's health and the family's perspectives.

Parents may describe a child's behavior as inconsistent with the "typical" pattern for a medical condition, or they may present alternative perspectives about the condition. Professionals should listen, validate the perspectives, and consider them with other information. Approach the child and family with openness, validation of their perspectives, and acceptance of family involvement.

6. Collaboration and linkages among family, school staff, and health professionals are essential to planning and conducting health-related activities in the classroom.

Parents can provide invaluable information, guidance, and assistance to school staff. School staff also should carefully gather information from family members about how health-related activities are performed at home and seek guidance in planning and conducting them at school. Parents can demonstrate a procedure to staff, who then develop written procedures with guidance from the child's parents and school staff, and the child's community health care provider.

Communication among everyone involved with the child's health is important. Parents should be informed of changes and concerns regarding health. They should provide written permission before information is shared with persons in the community. If parents hesitate about sharing information, reports can be provided to them so they, in turn, share information with persons they choose. Communication should be efficient, and information should be easily recorded, stored, and retrieved.[9]

Information can be stored by computer, allowing staff to record, report, and obtain information. Information systems allow the school nurse to enter information about a child's school health plan while other school staff also record observations that may affect some aspect of a child's health care. Information may be recorded using audio tape and later entered into a computerized information system. Take care when entering confidential information in a system accessible to others.

7. Parental knowledge of their child's health provides the basis for developing the Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP).

Determining parents' goals leads to developing health-related goals in the IEP or IFSP. These goals may includes wishes for a child's overall health status, desire for more information about the child's condition, or need to adapt classroom activities to more closely follow activities occurring at home. Information can be offered by parents or school staff to improve a child's overall health status. For example, adaptations made to tracheostomy suctioning procedures can accommodate characteristics of the child, preferences of family members, and current information provided by the school nurse.

8. Health-related issues should be included in the IEP or IFSP as appropriate.

Include health-related goals in the child's IEP or IFSP depending on the impact health issues have on a child's performance in school, and time required for activities such as tube feedings, suctioning, or other procedures at school. The child's educational program should include guidelines for all special health care procedures. Goals and objectives of the IEP or IFSP should relate to the child's overall educational program.[10]

Health care procedures such as seizure monitoring, teeth and gum care, and medication administration are conducted in 75% - 100% of classrooms serving children with severe multiple disabilities.[illegible] Health procedures are as much a part of daily living skills for some children as are dressing, grooming, and toileting. Since these procedures are educationally relevant for a child's independent functioning, they should be included in the child's activities and educational programming.[10]

For example, a child's gastrostomy tube feeding may occur during snack or lunch time. School staff may involve the child in activities to encourage communication, fine motor skill development, or socialization with peers. Creative approaches to integrating health-related procedures into the child's educational program will produce benefits to the child by increasing the sense of control over what is going on around the child, increasing mastery of self care skills, and optimizing time spent with the child.

9. Consider overall strategies to promote health and prevent further illness for the child in the classroom.

Children with special health care needs benefit from school experiences as they become involved with peers and age-appropriate activitieS. [illegible] School staff and parents should promote optimal health for the child by facilitating activities that promote health and intervening when activities adversely affect health. The child's parents, school nurse, and community health professionals usually are in the best position to consider specific ways to promote health.

Factors promoting health and factors leading to illness should be identified and appropriate strategies developed. For example, monitoring a child's weight and height over time can detect subtle changes in growth

Observation of growth patterns may prompt changes in the child's diet that prevent further health problems. A fragile child may need to leave school during an influenza outbreak or limit contact with peers and school staff.

CONSIDERATIONS FOR IMPLEMENTING THE GUIDELINES

1) Policies and Procedures for Communicating About a Child's Health. School policies should identify clearly what information will be shared, who will share the information with a child's parents, and how it will be shared. Verbal and written communication among family, school staff, and health professionals is crucial to promoting the child's health. Classroom staff must know how, when, and with whom to communicate concerns.

School staff need not be concerned about using medical terminology, but should report observations clearly in their own terms. Observations by school staff can provide useful information to the school nurse, the child's pediatrician, or pediatric specialist in making decisions about a child's treatment plan.

2) Policies and Procedures Regarding Training. Staff members implementing a health procedure must have appropriate training by an authorized health professional. In addition to training, maintenance of skills should be routinely evaluated. Persons working with the child should know their personal and professional limitations and ask appropriate persons for assistance. Telephone numbers of parents and others who can be called with written permission from parents must be on file and accessible to school staff. Written information intended for the child's parents must reach the parents.

The school nurse should be accessible to classroom staff as health-related issues arise. As students with special health care needs are integrated into regular classrooms, consideration must be given to availability of the school nurse to support and assist classroom staff. In turn, responsibilities of the school nurse must be modified to allow the nurse time for providing direct care and consultation, and for monitoring the care provided by others.

3) Health-Related Emergencies. Emergency procedures in school must be clearly outlined, as well as procedures for emergencies specific to a child. Written emergency procedures must be clear, easy-to-follow, and accessible to school staff. For many children with special health care needs, emergency situations can be anticipated and specific steps established. For example, a child receiving oxygen at school may experience abnormally slowed breathing. Specific steps to prepare for these periods may including repositioning, stimulation, and increase in oxygen flow when the child is receiving supplemental oxygen. A written procedure for this child's unique potential emergency is developed with guidance from the child's parents, school nurse, classroom staff, and community health professionals.

Unforeseen emergencies also may occur. A procedure known and understood by school staff must be in place for life-threatening situations. Written steps for the procedure should be placed near telephones and in each classroom. All school staff should be trained in cardiopulmonary resuscitation (CPR) and remain current through recertification.

4) Laws and Regulations. State laws and regulations regarding who can conduct health procedures in the classroom, who is responsible for performing these procedures, who is responsible for training others, and what level of supervision is needed must be clear to school staff. Interpretation of state regulations by the local board of education also must be understood. State and federal laws exist regarding services for children with special health care needs. Copies of state and federal laws requiring services to children with special health care needs in the community can be obtained from state agencies responsible for special education funding. Professionals in local school districts can be contacted about information on a district's policies.

In some states, nurse practice acts allow nurses to delegate health-related procedures such as tube feeding, suctioning, and seizure monitoring among others, to non-nursing school staff. School staff then can be trained to conduct a specific procedure, with supervision by the school nurse. This level of supervision usually is determined by the state's nurse practice act.

Written procedures developed by school staff and family members, with input from the child's physician, home health nurse, or others, should be in place.10 School staff willing to perform a procedure should be trained by appropriate persons. Ongoing modifications of procedure are made as changes occur for the child, the family, or in school. These corroborative efforts enhance the child's opportunities for optimal benefit from the educational program.

CONCLUSION

Careful communication among all persons involved in care of the child, proper use of existing systems in school, effective use of the IEP or IFSP to integrate health-related procedures into the educational program, knowledge of the child's health disorder, and consideration of implications of the disorder for the child in the classroom represent beginning steps to success for the child with special health care needs. Regardless of whether children with special health care needs have one or several health conditions, these students are more alike than different from their peers. The desired out-come is to promote optimal growth and development of children in school, at home, and in the community. School staff are accepting this exciting challenge as they work together with the child, the child's family, and professionals in the community to create safe, nurturing, and stimulating environments.

J. Carolyn Graff, RNC, MN, Director, Training In Nursing, Children's Rehabilitation Unit, Kansas University Affiliated Program, University of Kansas Medical Center, 3901 Rainbow Blvd, Kansas City, KS 66160-7340; and Marilyn Mulligan Ault, PhD, Program Associate, Dept of Special Education, 3001 Dole Bldg, University of Kansas, Lawrence, KS 66045. This article was submitted April 9, 1993, and revised and accepted for publication August 2, 1993.

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Individual Health Care Plans

by Dolores Harbeck

Although we serve all students in a school, there are some whose very life during the school day is a matter for our vigilance and expert knowledge. For them, the individual health care plan may mean the difference between attending regular school or not.

Historical Perspective

In the early 1980s the Aurora Public School District (Colorado) began facing the budgetary constraints that were affecting many school districts across the country. Consequently the number of school nurses serving the elementary schools was decreased and health aides were placed in each of the schools. At that time I was the only certificated school nurse assigned to carry out the health evaluations for the children who were referred from our 26 schools for special education evaluations under Public Law 94-142. It proved to be very nearly an impossible task and became a matter of trageing. A significant number of my evaluations were completed on children with serious and in some cases, potentially life-threatening conditions. As I became more aware of the numbers of such children, and as our district continued to grow rapidly and to receive an increasing number of children with health problems, I became very concerned about the fact that if a child's condition changed or worsened during the school day, the chance that a professionally trained health person would be there was remote. To address this concern, I developed the individual health care plans. These are written in such a way that they can be utilized in a practical manner by the nonmedical personnel in the school who are in contact with the child during the school day.

A plan is written for children who attend school and have a chronic or acute health problem that has the potential to cause a significant disruption of normal activities during the school day. Included among these conditions are:

- Diabetes
- Seizure disorders
- Moderate to severe asthma
- Severe allergies
- Cystic fibrosis
- Neoplastic disease
- Rheumatoid arthritis
- Encopresis
- Cardiovascular
- disorders
- Immune disorders
- Neuromuscular and musculo-skeletal disorders
- Respiratory disorders

Developing the Plan

One should attempt to follow a systematic procedure in developing the plan. The steps in the process are:

- Identify the child with a significant health problem.
- Meet with the parents to obtain a complete health history, particularly as it pertains to the significant health problem. I prefer to do this by means of a home visit if possible, in order to increase my rapport with the parents as well as to observe the techniques that the family uses to care for the child at home, especially in the case of a child with a significant physical handicap.
- Obtain a release from the parents to obtain information from the child's physician(s).
- Consult with the child's physician(s) and review previous medical reports.

Writing the Plan

1. List identifying information, ie., name, date of birth, school, grade or program, address, parents' names and home and work telephone numbers, and emergency contact persons.
2. List all physicians and health care providers, including their telephone numbers.
3. Enumerate the health problems.
4. Briefly describe each specific health problem, utilizing nursing and medical textbooks and/or medical specialists in the area.
5. List the precautions, treatments, and recommendations pertinent to the child and individualized for the child.
6. After completing the written portion, review the plan with the parents and obtain their signature. In more complicated cases, the physician's signature on the plan should also be obtained.
7. Determine the effective date for the plan, and enter it in writing.

In the process of writing the plan, continually bear in mind that it must be written using terminology that is understandable by nonmedical persons, because it has to become a workable document. Additionally remember that the above (see second page) general format may be followed but the plan must be individualized for each child. An example of a health care plan for a child with seizures, a pacemaker, and a history of strokes is shown in Figure 1.

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Implementation of the Plan

The plan is distributed to the appropriate personnel depending on the seriousness of the child's health problem. In our school district, the health aide and classroom teacher always receive a copy. In more serious cases the principal, school secretary, special teachers, i.e., art, music and physical education, playground aides; cafeteria aides and school bus driver, may also receive a copy. The parents are also given a copy. I then give instruction to the persons receiving the health care plans. During this instruction I explain each step of the plan and answer questions. Instruction is preferably given to a group and in the morning before the Start of a school day in order to accommodate each individual's schedule. As part of the inservice instruction, the responsibility for maintaining confidentiality regarding the information contained in the care plan is highly stressed. If possible, the parents are included in the inservice meeting.

This plan should be reviewed and updated at appropriate intervals and as soon as possible in the event there is a significant change in the child's condition.

Advantages of Utilizing Health Care Plans

I have found in the past six years of writing health care plans that they offer several benefits. First among them are that parents express more confidence about sending their child to school when they know that a health care plan is in effect, and that the teachers and other responsible adults know what actions need to be taken when the child has a health problem at school.

Additional advantages are that care plans help to dispel rumors and inaccurate information regarding the condition of children who are visibly physically impaired.

The care plan helps to decrease the apprehension of the nonmedical personnel in the school and increases their self confidence in their ability to handle potential emergency situations. There is a feeling of control over the situation because they have a tangible object—the care plan—to follow step by step in the event of an exacerbation of a health problem. The plan also provides a measure of reassurance for the school nurse that emergency situations will be managed safely in her absence. From my viewpoint health care plan development is an excellent way to use the unique expertise that the certificated school nurse brings to a school district by virtue of education and experience.

An unforeseen result of the establishment of the health care plan in the Aurora School District is that the central administration and the school board have increased the number of nurses serving the elementary schools since 1983 from one to four. The health care plan is a tangible demonstration of the nature of the health problems of an increasing number of children who are enrolling in our public schools. It is also a document that clearly displays the distinctive role of the school nurse as direct care provider.

About the author—
Dolores Harbeck, RN, BSN, NP is Elementary
Itinerant School Nurse for the Aurora Public Schools, Aurora, Colorado.

Figure 1

Aurora Public Schools
Department of Special Education
Lansing Annex 11023 East Fifth Avenue
Aurora, Colorado 80010

INDIVIDUAL HEALTH CARE PLAN FOR (Student's Name)

STUDENT ____________________
SCHOOL ____________________
DATE ____________________
EFFECTIVE ____________________
COMPRECARE: TEL. NO. ____________________
GROUP # ____________________

BIRTHDATE ____________________
GRADE/PROGRAM ____________________
PARENT ____________________
PARENT ____________________
HOME PHONE: ____________________
WORK PHONE: (mother) ____________________
(father) ____________________

PHYSICIANS:
1. Dr A-Pediatrician, telephone number
2. Dr B-Neurologist, Children's Hospital telephone number.
3. University of Colorado Health Sciences Center, Cardiology Department C.R.N.

EMERGENCY CONTACT PERSON IF BOTH PARENTS ARE UNAVAILABLE:

PROBLEM #1 - Seizures

W has grand mal focal and petit mal seizures. His seizures began at 18 days and occur frequently and sporadically, although primarily in the early morning. He is followed by Dr. B at Children's Hospital. He currently takes Depakane, 1500 mgm a day and Tegretal 700 mgm a day. All medications are taken at home. SPECIFIC PRECAUTIONS:

1. Prior to a grand mal seizure, he frequently complains of nausea.
2. If he complains of nausea or begins to display signs of a grand mal seizure:

STAY WITH HIM DURING SEIZURE.

  a. Ease him to the floor onto his abdomen and away from hard or sharp objects.
  b. Make certain that his airway is open by turning his head to the side.
  c. Do not put anything in his mouth.
  d. If the seizing activity lasts more than 10 minutes, call 911.
  e. After calling 911, call Dr. A's office. Give Comprecare numbers, group number. Request instructions regarding which hospital he is to be transported to.
  f. Tell paramedics that he has a pacemaker implanted.
  g. Have someone call his mother.
  h. If seizures lasts less than 10 minutes, allow to rest in health office and call mother. Note on heath record, length of time of the seizure and any unusual events occurring prior to or during the seizure.

3. Focal Motor - W's symptoms of a focal motor seizure consist of spastic movement of the left arm and lack of awareness of his surroundings. These symptoms may last up to 4 or 5 minutes. After the movement ceases, he will complain of headache and possible nausea.
  a. Allow to rest in the clinic, he may fall asleep. Observe closely.
  b. Call mother.
  c. When he becomes alert and oriented, if he complains of headache, give him Tylenol per mother's written instructions.
  d. Do not allow playing on high equipment in P.E. or on playground.
4. Petit Mal Seizure - W's symptom consists of a simple staring spell which usually lasts less than a minute. No special first aid treatment is needed.

PROBLEM #2 - Pacemaker implant

W had open heart surgery at one day of age due to transposition of the great vessels. He had subsequent surgeries at age 2 and age 7 to implant a pacemaker. He will have monthly pacemaker checks via the telephone for a tele-track transmission with C.R.N. Cardiology Department, University of Colorado Health Sciences Center, hospital telephone. The apparatus needed for the check will be kept in the school heath office. W's pacemaker is located below the sternum and directly above the navel and is implanted under the skin.

Specific PRECAUTIONS:

1. No jumping from hi places or distance or on trampolines.
2. No hard blows to the abdomen.
3. No contact sports.
4. If he complains of chest pain or dizziness, contact Pediatric Cardiology Unit, telephone number.
5. If he falls asleep in class, pallor, or increased fatigue are noted, notify mother.
6. He must avoid contact with magnets or radio or television antennas which could emit radio waves as they will cause his pacemaker to malfunction. He may be around microwave ovens.

PROBLEM #3 - History of Strokes

W has had two known strokes both affecting his left side. The first one occurred at 3 days of age. The second at 15 to 20 months of age. Both were thought to be due to side effects of his open heart surgery. The residual effects are left sided weakness. He has received extensive physical therapy and occupational therapy relative to the weakness.

PROBLEM #4 - Socio emotional Concerns

W is apparently very self conscious and concerned about his seizure activity. He is apprehensive about having a seizure in the classroom or on a field trip. SPECIFIC PRECAUTIONS:

1. Reassure W that all of the school staff that he will be in contact with, both at school and on field trips, are aware of the first aid measures needed in the event of a seizure.

W's classmates should receive instruction about seizures in order to increase their understanding and acceptance.

Signature of nurse preparing report ____________________

Parent ____________________ Physician ____________________

APPENDIX Q

MODEL NURSE PRACTICE ACT: ORDERING INFORMATION

A Model Nursing Practice Act (1994) presenting model legislation has been prepared by the National Council for the review and revision of state nursing laws. The Model includes language regarding advanced nursing practice.

To order contact the National Council of State Boards of Nursing, Inc., Dept. 77-3953, Chicago, Illinois 60678-3953. Price $12.00 plus $2.00 shipping and handling.